The ME Global Chronicle

www.let-me.be

 # 35 –March 2020

1. Colofon / Personalia

Advisor: ***Leonard A. Jason***

Editor/Editorial team: ***Colleen Steckel, Eddy Keuninckx, Rob Wijbenga***

To this joint worldwide effort contributed in one way or another:

Action for ME
Amanda J. Charlton
Barbara Fifield
Brenda Vreeswijk
Brent Merritt
Colleen Steckel
Corina Duyn
Darda Anderson
David Tuller
Deutsche Gesellschaft für ME/CFS
Dr. David Newton
Dr. Nancy Klimas
Dr. Nigel Speight
Dr. Rosamund Vallings
Eddy Keuninckx
Emerge Australia
Emily McGarvey
Erica Verrillo
Evelien van den Brink
Evelyn Ring
Gabby Klein
Gertrud U. Rey
Giada da Ros
Groep ME-Den Haag
Herman Jan Couwenberg
Jan Johnson
Jelle Bouwhuis
Jen Temm
Jennifer Brea
Jessica Taylor-Bearman
Josh Biggs
Karman Kregloe
Kathleen Morgan
Lorna Bryson
ME Advocacy.org
ME/CFS.cz
#MEAction
Michiel Tack
Mike Harley
Millions Missing Finland
Millions Missing France
Naomi Whittingham
Natalie Boulton
Open Medicine Foundation
Pam Lutey
Prof. Leonard Jason
Prof. Sonya Marshall-Gradisnik
Retha Viviers
Rob Wijbenga
Stacy Hart aka @MamaChill
Sten Helmfrid
Stine Aasheim
Sture Eriksson
Suzy Chapman
Sylvia Iversen
Team Dutch US
The Mighty
Tom Kindlon
Tom Tahavsky

Distribution & Layout: ***Eddy Keuninckx***
Archive: https://let-me.be
Facebook: *https://www.facebook.com/groups/TheMEGlobalChronicle/*
The editorial team doesn't accept any responsibility for any possible incorrect information that it has been supplied with and which has been published in this issue. Anyone can subscribe to this free magazine by sending his/her email address to: subscribe@let-me.be. You can un-subscribe by sending a mail to: unsubscribe@let-me.be. Textual contributions for the June issue need to be supplied in Word by 26th May and sent to: contribute@let-me.be. The next issue will come out on June 22, 2020.

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

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

2. Table of Contents

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

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

3. Editorial

Dear friends,
We're happy to announce the advent of the next ME Global Chronicle, thanks to your contributions. We're in this thing together after all; the mere act of reading the magazine or just an article or glancing through it is a contribution as well and not less important.

An odd time is upon us, seeing as the year has started off with a pandemic which looks to only spiral more out of control. This is also the reason why several data-based articles in this edition may contain inaccuracies. For this, we sincerely apologize.

Once again, we would like to draw attention to the European Petition dedicated to acknowledging and directing funding towards bio-medical ME. It can still be signed and submitted until the beginning of April by anyone of any age. There were already more than 13,000 signatures two weeks ago, which is unique for a European Petition, and more and more have flooded in since! Let the European Parliament know that all eyes of the ME-sphere are on them...

We will continue to promote the American petition as well. That way, everyone is able to actively participate in shaping a better world for ME patients across the globe.Then there's the usual ME-related news, like in every edition - scientific articles, a column, a poem and a plethora of grassroots activities can be found this time, as well as news from 16 countries.

- ⇨ Also the instructions for navigating pages like always: click on the desired article in the Table of Contents to be sent to that page. You can return to the Table of Contents at any time by clicking 'Back' at the bottom of the page.

Speaks for itself what we're including in each issues are just snapshots from here and there. To describe what is happening all over the world in the field of M.E. would cover the pages of an entire book each quarter. Contributions to June's release are to be submitted via contribute@let-me.be before the end of May. Preferred format and font: Word, Verdana (size 12).

We hope this will be an enjoyable read, and wish everyone on the Southern Hemisphere a lovely fall, and those on the Northern Hemisphere a refreshing spring with less Corona-distress.

March 2020, the editors
Colleen Steckel
Eddy Keuninckx
Rob WIjbenga

4. Dutch Citizen Initiative

ZonMW and ME

Ever since the meeting of patient representatives with a delegation of **Minister Bruins** (Public Health) and ZonMW in March 2019 a lot has been accomplished. Even though the work involved for that has not been visible during the last year.

ZonMW is the Netherlands Organization for Health Research and Development.

A short and concise update, in which we attempt to compensate for that lack of information.

ZonMW and Group ME-The Hague, the ME/CFS Association, the Support Group ME and Disability and the ME/CFS Foundation have had 4 meetings since, in which a foundation has been laid for an Action Plan for a research agenda, which the Minister of Health had instructed to create.

This AP provided a trajectory of one and a half year to create this research agenda. By intervention of the Minister this is to be shortened to half a year. This happened as a result of questions and pressure from MPs, to urge him for quicker results.

In the meanwhile ZonMW, in part but not completely by instruction of patient organisations, has searched for potential contestants for a Steering Group that will set up the research agenda. This Steering Group also has to provide tools to increase awareness about the biomedical illness ME in all levels of health care in our country.

This Steering Group is not yet fully staffed. The two vacant seats should be allocated to researchers already familiar with ME, even though the capacity, willingness and knowledge of the scientists that have already confirmed their cooperation are very promising.

Nevertheless, all four of the patient organisations have urged ZonMW to fill the vacancies with ME researchers which Group ME-The Hague has suggested. Additionally, Group ME-The Hague has handed several clear tools to consult the most ground breaking ME research groups in the world, as a starter point for setting up the research agenda in the Netherlands.

Earlier this month the Steering Group, in its current formation, has already been installed by the CEO of ZonMW and the first exchange has already taken place.

The earlier mentioned Action Plan has been the basis for ZonMW to create a Notification of Intent as a foundation of this first exchange. The research agenda has to not only come up with suggestions for a research program, it also has to decide on a budget for the program (as for example promising research directions), which will then have to be approved by the Minister.

The foundation of the whole trajectory is the final report of the Health Council ánd the demands of the Civilians Initiative (https://bit.ly/2uJaLQg) that has lead us here. This means that research suggestions have to be of biomedical nature, with proper assessments of the research cohorts.

Group-The Hague will watch over that as well, to make sure it will happen that way. After all, they feel a responsibility for 56.000 civilians that signed their petition, among which the majority of all ME patients in the Netherlands.

That does not alter the fact that Group-ME The Hague will keep providing their knowledge, networks and energy to create a result that is as optimal for patients as possible. Because that is the only goal we have in mind.

A recent update about the progress ZonMW's research agenda steering group has made you'll find under the heading News from the Netherlands.

Rob Wijbenga on behalf of Groep ME-Den Haag

5. WHO and SNOMED CT News

Update to my Report on Classification of PVFS, ME and CFS for ICD-11

ICD-11 Report Two | February 2020

In the December edition, I set out how the G93.3 terms: Postviral fatigue syndrome; Benign myalgic encephalomyelitis; and Chronic fatigue syndrome are classified in the WHO's international version of ICD-10 and how these terms have been classified for ICD-11.

I have an update on ICD-10 and it's good news! In January, the WHO released ICD-10 Version: 2019. With ICD-11 on the horizon, this release will be the final update for the WHO's international version of ICD-10.

In 2016, a representative from the Canadian Institute for Health Information submitted a request and supporting rationale to the ICD-10 Update and Revision Committee (URC) for removal of the prefix "Benign" from "Benign myalgic encephalomyelitis". This request for a change was approved by the URC in September 2016 for implementation in the next release.

The ICD-10 Version: 2019 Tabular List G93.3 inclusion term is now "Myalgic encephalomyelitis". (The term, "Benign myalgic encephalomyelitis" has been retained as an Index term.)

I have updated the PDF included in my report in the December edition to reflect this change and to include a screenshot.

Download the PDF of my updated report here: http://bit.ly/ICD11Update

Or view the revised listing for G93.3 here:
https://icd.who.int/browse10/2019/en#/G93.3

The WHO expects Member States to be using the most recent release of ICD-10. But countries will implement this new release according to their own schedules.

NHS England currently uses ICD-10 Version: 2016. I have contacted NHS Digital's classifications lead to establish whether NHS Digital intends to implement Version: 2019 or may be considering skipping the new release in preference to implementing ICD-11, at some point in the future. If there is no mechanism for incorporating selected changes in a new release into earlier versions, NHS England might not be able to absorb this change into the version it is using.

This revision sets a precedent for the national modifications of ICD-10, for example, the U.S. ICD-10-CM and Canadian ICD-10-CA, but also for ICD-11.

Proposals submitted in March 2017 by **Chapman** & **Dimmock**, and by the IACFS/ME for removing "Benign" from "Benign myalgic encephalomyelitis" were rejected by the WHO in early 2019. In February, I submitted a new proposal for removal of the "Benign" prefix for ICD-11 citing the URC's 2016 decision and the implementation of that decision for the final release of ICD-10.

You can read a copy of my new proposal and rationale here:
http://bit.ly/BenignICD11

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

NHS Digital Requests Addition of SEID to SNOMED CT

SNOMED CT Report One | March 2020
The UK Edition of SNOMED CT terminology system is managed by NHS Digital.

Authorized users can register to submit requests for changes or additions to the terminology system via the NHS Digital submission portal [1]. Requests that meet criteria for potential addition to the SNOMED CT International Edition are referred on for consideration by SNOMED International's terminology specialists. Members of the public can access a database of requests submitted since late 2008 and monitor their progress through the review process and their outcome. On March 12, I noticed that a request had been submitted in November, last year, for adding the term "Systemic exertion intolerance disease" to SNOMED CT [2]:
View Request 30104 on NHS Digital Submission Portal: http://bit.ly/39Pz4vy
or view a screenshot here: http://bit.ly/3aSzSjp

Please note:
1 Request 30104 was submitted on November 30, 2019. It appears to originate from within the NHS (or other authorized user) as no other class of stakeholder is referenced as the original requester. The request's priority is designated "Minor".

2 The request is for adding the term "Systemic exertion intolerance disease" as a Synonym under SNOMED CT Concept: 52702003 Chronic fatigue syndrome.

3 Brief summary of the request: "Synonym request due to renaming in some international health services"

Description of the addition or change:
"Hi team, the US Institute of Medicine renamed CFS/ME in 2015. While CFS/ME will likely remain the terms used within the UK, a lack of this synonym could create difficulties in correctly identifying diagnoses in records crossing borders etc. The addition of the term would also allow UK records to accurately reflect a diagnosis originally made in the USA while still maintaining data quality for UK identification of CFS in health records/databases etc. https://bit.ly/2Umpjyy - https://bit.ly/2UjyHTw"

4 At the time of drafting this report, the request's review status is "Referred to SNOMED International" and assigned request referral number: 748360.

5 A senior member of SNOMED International's staff confirmed that this request has been submitted for addition to the SNOMED CT International Edition. If the term "Systemic exertion intolerance disease" is approved for adding to the International Edition, this additional Synonym term under CFS would be absorbed by all the national editions when they release their next updates [3].

6 The requester's description text states: "...the US Institute of Medicine renamed CFS/ME in 2015." However, the US Institute of Medicine (IOM), now known as "The National Academy of Medicine" (NAM), did not "rename" CFS/ME in 2015. The external panel assembled by the IOM to undertake an evidence review and formulate recommendations had included the suggestion for the name "Systemic exertion intolerance disease" as one of a number of Recommendations put forward in its 2015 Report for review and consideration by the sponsor agencies [4].

7 CDC has not adopted the term "Systemic exertion intolerance disease": In preference, CDC uses "ME/CFS" on its website clinical information pages and "ME/CFS" for its Continuing Medical Education (CME) activities.

8 Field testing: The IOM panel's suggested case definition has not been subject to field testing by, or on behalf of the CDC. Several studies published since the Report's release concluded that the proposed SEID case definition lacks reliability and specificity; discussed the unintended consequences of not specifying exclusionary illnesses; and noted the lack of acceptability to patients of the SEID nomenclature and proposed case definition.

9 ICD-10-CM: NCHS-CDC have not added the SEID term to ICD-10-CM, an adaptation of the WHO's ICD-10, that is mandatory in the US for assigning diagnostic codes for medical billing and reimbursement. Proposals for the potential addition of the SEID term were presented for discussion by Donna Pickett (CDC) at the September 11-12, 2018 meeting of the ICD-10-CM Coordination and Maintenance Committee [5]. Following the stakeholder review process, no decision to approve was arrived at by NCHS's Director and no revised proposals or new proposals have been presented at subsequent C & M meetings.

10 ICD-10: The term "Systemic exertion intolerance disease" has not been added to the final update of the WHO's international edition of ICD-10 (Version: 2019).

11 ICD-11: The IOM panel's Report formed part of the literature review for the potential revision of the ICD-10 G93.3 legacy categories. WHO and ICD-11 CSAC and MSAC committees do not propose including the SEID term in ICD-11.

12 SNOMED CT US Edition: The term has not been added to the SNOMED CT US Edition, either as a new Concept code, or as a Synonym or Child under Concept: 52702003 Chronic fatigue syndrome. A couple of minutes on Google demonstrates that some websites providing clinical information to physicians, healthcare professionals and patients are referring to "Systemic exertion intolerance disease" as though the term had been adopted by US federal agencies when this is not the case — it remains a Recommendation.

As the IOM panel's suggested term has not been adopted by US federal agencies; as the proposed case definition has not undergone field testing; and as NCHS-CDC has made no decision to include a code for the term in the US's ICD-10-CM, it is premature to approve a request for addition to the SNOMED CT International Edition.

On March 12, I discussed this request with SNOMED International's Rory Davidson who has passed on my concerns to SNOMED International's terminology leads. A copy of this report has also been provided.

References:

1 NHS Digital SNOMED CT Submission Portal: Request 30104: http://bit.ly/2vsuPHn

2 NHS Digital SNOMED CT Browser: http://bit.ly/38OqL1R

3 SNOMED CT International Edition Browser and 13 national edition browsers: https://browser.ihtsdotools.org

4 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); Feb 2015. https://www.ncbi.nlm.nih.gov/pubmed/25695122

5 ICD-10-CM Coordination and Maintenance Committee Meeting, September 11-12, 2018, Diagnosis Agenda Part 2, Page 11: Chronic Fatigue Syndrome: https://www.cdc.gov/nchs/data/icd/Topic_packet_Sept_2018_part2.pdf

About SNOMED CT:

Clinical classifications like ICD-10, and the SNOMED CT terminology system are complementary and serve different purposes. ICD-10 is used after the event by clinicians and coders and focuses on diagnostic coding and data recording for statistical and epidemiological analysis, reimbursement and resource allocation.

SNOMED CT is used by clinicians in electronic medical records (EMRs), at the point of care, to record findings, symptoms, diagnoses, interventions, procedures etc. Each clinical concept or phrase is assigned a unique SCTID code to provide a standardized, machine readable terminology for recording and sharing clinical information across multiple health care settings. SCTID codes are mapped to ICD-10 and to ICPC-2e codes for interoperability.

SNOMED CT is considered to be the most comprehensive, multilingual healthcare terminology in the world. It is used in over 30 countries and is the recommended terminology system in the UK, US, Canada, New Zealand and Australia.

SNOMED CT International Edition releases two updates a year. A number of countries maintain national editions which automatically incorporate the updated content from the core SNOMED CT International releases but may also include country specific terminology. The national editions release twice yearly updates on a staggered schedule and their current content may not reflect the changes and additions to the most recent release of the International Edition.

SNOMED CT does not regulate which concepts should or should not be used in clinical records, but makes concepts available in response to requests from stakeholders and in accordance with its editorial and content development principles [1].

Since April 2018, SNOMED CT UK Edition has been the mandatory terminology system for use in NHS primary care, replacing the Read Code (CTV3) terminology system, which is now retired. SNOMED CT UK Edition is scheduled for adoption across all clinical, secondary care and mental health settings from April 2020.

Browsers for the SNOMED CT International Edition and the national editions for Australia, Belgium, Canada, Denmark, Netherlands, Sweden, US and a number of other countries can be accessed here:

SNOMED International SNOMED CT Browser http://browser.ihtsdotools.org

The SNOMED CT UK Edition is managed by NHS Digital, as the designated UK National Release Centre. A public browser can be accessed here: https://termbrowser.nhs.uk

1 SNOMED CT International Release Content Development:
https://confluence.ihtsdotools.org/display/DOCSTART/9.+Content+Development

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

6. Grassroot

The ME Debate is Raging Again

The ME debate is raging again, and once again the core of the battle is the role of the psyche in this disease. The debate loops. It has been doing this for many years. Fafo in the autumn interviewed 24 families affected by ME. We have been all over the country and interviewed sick and relatives in various stages of illness, different family constellations, ME association members, non-members and the unregistered. These qualitative interviews will be supplemented by survey and register data in the ongoing service and MEg project.

In our experience, one of the elephants in the room in the ongoing and seemingly polarized debate is that when the parties talk about psyche, in practice they talk about two quite different things. Many people do not claim that this disease is only mental or only somatic.

In our wide range of ME-affected families, everyone sees that both the mental and the physical are at stake in the disease. A polarization between those who believe the disease is only mental and those who think it is only physical becomes a trivialized over-simplification of the various positions. In the conversations we have had with resource persons in the professional environment, we also do not think we have talked to anyone who thinks the disease is not affected by the psyche, just as with other somatic diseases. For example, the (Norwegian) ME Association does not appear to us as a representative of a position where the disease is to be understood as solely somatic. In the same way, the Competence Service appears to us as far less dogmatic than the position they are easily given in the heat of the fight.

The big question therefore becomes what the debaters really mean when they talk about the mental component of the disease. And here it may seem to us that the parties are talking about different things. There appear to be two different positions, both of which are referred to under the label "psyche", and can be roughly simplified to describe the following:

- Patients are sometimes shocked to experience such a severe loss of function as those experienced by ME sufferers. Untreated shock for some goes into poor mental health and even depression. If you continue with both a physical loss of function and a depression, negative synergies will be created between the two. Such synergies are likely to appear to exacerbate both disease and exacerbate disease. Several ME sufferers we interviewed have sought psychological help to cope with this process, but some say that this has been rejected on the grounds that "ME is not a mental illness". Psychological assistance could undoubtedly help ME sufferers to process and manage shock and possible depressive development, thereby also alleviating disease-worsening and disease-extending synergies.

- The second position relates to the idea that some people have "dysfunctional thought patterns" that alone or in conjunction with lighter somatics create illness. Quite uncontroversial examples of this can be found in several cases of phobias. These phobias can now be cured partially or completely with newer cognitive methods. And there are such methods recommended by ME sufferers. ME is then interpreted as a form of activity phobia, which, for example, may have bodied and developed in connection with a previous somatic disease.

Phobic anxiety can be experienced as powerful physical reactions, but the fear component itself is obvious, and easily recognizable as psychic. We must assume that people with phobias are largely aware that their fear of going out, dealing with birds, or talking in a congregation is an irrational anxiety that stems from the brain. They know that birds are not dangerous. We must therefore also assume that it will be perceived as less problematic to be told that they have "dysfunctional thought patterns" which, if challenged, can be altered and thus cure the disease.

It is different with ME. People with ME rarely / do not experience their illness as psychic, it manifests itself in very physical forms. Obvious mental disorders should also be the exclusion reason for the ME diagnosis according to the recommended Canada criteria. But they say that, especially in the early period of illness, they are horrified that everything they like to do, which has previously given them pleasure and profits, now punishes them with various forms of violent physical breakdowns.

The mental adjustment from ordinary life to such a condition is shocking, and, just as with some other serious diagnoses, produces significant psychological reactions. We have so far concluded that a major cause of the level of conflict between ME sufferers and the system is the gap that exists between many sufferers' experiences of their own illness and the explanatory models they encounter with from the health and welfare systems.

They simply feel that their narrative of illness without the embrace is objectified as a manifestation of a kind of madness; the dysfunctional thought patterns. We think resistance in such a situation would apply to very many patient groups, it is basically very human to respond when one's reality experience is met as a form of imagination.

An example of how ME sufferers in this way feel less taken seriously is about driving a car. In our sample, two completely different informants told me that at one point they experienced a functional loss, especially brain fog, which was so challenging that they considered it irresponsible for them to drive. Both had then been offered cognitive therapy to overcome their "car anxiety".

Their own experience of being sick in such a way that they were incapacitated in traffic was thus rejected as a manifestation of a form of irrationality and imagination. While it may be difficult for ME sufferers to receive psychologic help, most people reported on participation in the course of cognitive therapy, especially in connection with rehabilitation stays. In our selection, none of the informants had, so far as we have analyzed our material, experienced improvement after such costly rehabilitation stays. On the contrary, many reported worsening illness.

We call for a systematic evaluation of what appears to be a costly and poorly results-based public prioritization of measures for ME sufferers today. There are some unexplained illnesses in the world today. Some of these conditions will prove to be mental. Others we will find biological explanations for, in the same way as with endometriosis and thyroid disease, previously attributed to hysteria. What is certain, however, is that we are not at the end of history, purely in terms of research.

More humility that both explanatory models may be better documented in the future is therefore called for. And as the ME-sick respondents told us: We do not care if the cure for ME is medical or psychological. We just want to be listened to, respected - and healthy again.

Submitted by **Stine Aasheim**

Source: http://bit.ly/334qiXS

MEadvocacy.org Advisory Committee Member Selected in Remarkable Women Contest

March is International Women's Month. In recognition of the influence that women have had on public policy, social progress and the quality of life, NexStar Media Group launched the "Remarkable Women" nationwide initiative. MEadvocacy made TV news in Eastern North Carolina when, **Colleen Steckel**, one of our advisory committee members was interviewed by WNCT multimedia journalist **Katie Augustine** as a local nominee for "Remarkable Women". See details at https://bwnews.pr/3a6Hoqo

The video of the interview quickly spread through social media with over 5,200 video views since originally airing on Feb 11, 2020. See video here:
https://www.wnct.com/local-news/remarkable-women-colleen-steckel/

Colleen is one of four women nominees from her local area. On March 6, one of these women will be selected to go to New York to attend The Mel Robbins Show where the winner of the Nexstar Woman of the Year will be announced.
We are grateful that **Colleen**'s husband, **David**, nominated her which led to an interview in their home.

This is a unique opportunity for myalgic encephalomyelitis (ME) to be seen by a wider audience and bring much-needed recognition to ME as a distinct disease.
MEadvocacy's "Resources" page (www.MEadvocacy.org/resource), which contains valuable information on ME, was mentioned in the interview, as well as the ME International Consensus Primer for Clinical Practitioners.

NOTE: Those in the EU can view the video uploaded by WNCT to their Facebook page at http://bit.ly/336N3uC or by visiting MEadvocacy.org's Facebook page at https://www.facebook.com/MEadvocacy.org/

To learn what you can do to help, read entire blog at: http://bit.ly/38DGLDI

Recognizable?

Note: While this is about RA, these coping techniques apply to ME as well. There is a large overlap both in pathology and symptoms between ME and RA. The editors.

Rheumatoid arthritis (RA) is one of the most common types of arthritis, affecting approximately 1.5 million Americans. Not all forms of arthritis are considered autoimmune, but RA falls in this category since the disease involves the immune system mistakenly attacking the joints. This leads to inflammation that causes the tissue inside the joints to thicken, resulting in pain and swelling.

The effects of rheumatoid arthritis aren't limited to the joints, though. RA can have an impact on other bodily systems, such as the cardiovascular or respiratory system, as well as a person's mental well-being and ability to do everyday tasks.

To cope with the many symptoms and side effects RA can cause, some people may find themselves developing certain "habits" or engaging in routine behaviors that help them through the challenges they face.

- "I schedule everything with an extra hour in front of it. Appointments, grocery shopping, going places… because sometimes I get cocky and play myself! Lol!" – **Dana C.**
- "Downplaying how bad something actually hurts based on how I feel every day or assuming that something is going to go away soon when I know it won't." **– Lauren O.**
- "Inadvertently popping my joints because they feel so tight and hurt so bad." – **Rebecca K.**
- "Resting on my days off." – **Ambra D.**
- "Clenching my teeth with the pain. I have a couple of chipped teeth now." – **Jen A.**
- "I've seriously deprived myself [of] letting go of who I used to be, and developed the bad habit of always being too hard on myself. I keep trying and trying to make myself believe I'm still the same functional person I used to love. I can't let go, I can't accept this feeling. I wake up everyday feeling like I'm in someone else's body, living someone else's life, not mine. Now I can't even remember the feeling of who I used to be." – **Liz G.**
- "Learning strong boundaries because I physically can't do things." – **John H.**
- "I've learned to exercise in new and different ways. I have become a more curious and open human being by seeking out and learning low impact exercises." – **Heather Y.F.**
- "What I call 'hands choreography.' My friends [have gotten] used to it by now." – **Ye'ela B.**
- "[I'm] too scared to do mostly anything anymore because it swells my joints and causes way too much pain. I've developed extreme anxiety and try to work through the fear as best I can. Fear of not being able to even get out of bed because I decided to go to work that day…" – **Katlyn S.**
- "Saying I'm fine when I'm not." – **Jill C.**

- "This may sound weird, but when a joint is flaring, I gently rub it without realizing I'm doing it. And when my hands and wrists flare and are giving off lots of heat, I hold them up to my cheeks to warm my face." – **Alyson A.K.**
- "Taking naps when I can." – **Angie H.**
- "I take a picture of every joint when it's flaring. The doctor never believes your level of pain nor the severity of each flare." – **Kristin W.**
- "I have had to be much more aware of my lifestyle choices like foods I eat and dealing with stress. I have made so many positive changes I decided to become a health coach so I can help others make positive changes too." – **Valeri T.**
- "Take the elevator no matter what!" – **Katelyn W.**
- "I constantly say sorry for being sick. As if being sick is inside my control." – **Heather Y.F.**
- "Rocking my body for comfort while in pain. For some reason it soothes me. Side to side or front to back rocking. Doesn't matter. Just rocking my upper body." – **Carol S.**
- "Live in the present, take things one day at a time. Don't take things for granted." – **Jenny S.**

Source: The Mighty http://bit.ly/2TQyZ48

#MEAction - #MillionsMissing

Dear All,

The situation of COVID-19 is rapidly changing. We wanted to be optimistic that this situation would improve for the better, but even in the last 48 hours the situation has dramatically shifted. The WHO is officially classifying the virus a pandemic (http://bit.ly/2IShLOI). COVID-19 is now affecting more than 180,000 (http://bit.ly/3d3KRIN) people worldwide.

We can't in good conscience, continue with in-person #MillionsMissing events. We care about the health of you and every person that would have come to these events.

We are still doing #MillionsMissing on May 12th. It will all be virtual. Our community has always had a strong, powerful, and supportive virtual presence. This event will be no different.

We believe we can use this moment to build our virtual movement and community and come together in solidarity with all of the #MillionsMissing around the world.

We have decided not to reschedule later in the year, because dates in the future are also uncertain, but this virtual event will be strong, supportive, and a time for our community to come together. A chance to be joyful and resilient in a time of uncertainty.

We will be creating a form to share your ideas and brainstorm with us for our virtual #MillionsMissing as well as a link to RSVP and get updates.

Moving forward, responding to Covid-19 coronavirus will remain a top priority for all staff and volunteer efforts until the situation is brought under control. #MEAction will continue to rapidly identify the tools, teams and resources we can bring together to support our community through this situation. Tomorrow, we will be sharing more information and a webpage dedicated towards Covid-19.

In spite of all the challenges before us, once again, we believe the #MEAction community can use this moment to build our virtual movement and community and come together in solidarity with all of the #MillionsMissing around the world.

In solidarity,

Jen, **Laurie**, **Ben**, **Erin**, **Jaime**, **Espe**, **Holly**, **Adriane**, **Hannah**

Marathon Mike

Italy & ME – part 1

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

Mike:
It's estimated that around 500,000 people have ME/CFS in Italy. I've been finding out more about how the illness affects people there.

How did you get ill?

Fabio - I was 24 years old, in 1998, when I contracted an acute case of mononucleosis, the doctors feared in the first place that I had contracted the HIV virus, because I had the lymph nodes as large as tennis balls and high fever. The worst, however, came later: I get tired with incredible ease, I go to bed early every night. In short, never go out in the evening.

When I come back from work, I don't want to speak or meet anyone, including my parents, because I'm so tired. At first the neurologist said I was OK and that it was "all was in my head" then they said I was depressed (he prescribed me SSRI which made me more tired). The haematologist suggested me to do some shopping! (I thought "of course, with your credit card, please!"). During the progression of the illness I developed worsening idiopathic hypersomnia, gastroparesis, dyspepsia and consequent Methane-SIBO (Small Intestine Bacterial Overgrowth with constipation), due to bad functioning of the vagus nerve.

Giada - I got ill following a flu. Or at least this is what I think. I was 20 (it was 1990) and attending university. I started having these huge dizziness spells and I felt sick with flu-like symptoms (sore-throat, fever, muscle and joint migrant pain, brainfog, fatigue…), but I was busy with classes and exams and didn't give it much attention save for a few days in bed. In the beginning I didn't even realize how predominant fatigue was, I just felt sick.

Then, the flu was gone but I was not healthy anymore. I used to do something very normal, like taking grocery store bags to the first floor where I live, and I needed a couple of hours to recuperate the fatigue. In the very beginning I thought that I was perhaps out of exercise – even if I used to lead an active life – so I tried to do that, but I soon stopped because it would make me worse for days. Within 6 months – a year, I was completely bed-ridden.

Rosa - I don't know how I got sick but I was a child when I started to feel weak and without strength, I remember around the age of 10 some terrible pains in my ears that the doctor couldn't explain and from then on I changed deeply.

Chiara - My son **Valerio** and I have CFS ME, I got sick at 19 years old after a pure viral form, three days of very high fever and no other symptoms; Valerio after the first dose of the hepatitis vaccine, but it was a pure coincidence, even if Professor Tirelli told us that it can happen.

Has it been difficult to get diagnosed?

Fabio - I got mono and my life has been cut in 1998, I only got a diagnosis in 2010, after about 10.000 Euros spent in public (Italian NHS) tests and visit.

Giada - Fortunately, it wasn't particularly difficult. The leading Italian expert on CFS/ME lives in my town. He often does interviews with TV and papers. I read an interview on a paper regarding what was at the time just called Chronic Fatigue Syndrome and it was my description. I went straight to him. I got ill at the end of 1990 and I received my written diagnosis on February 15th 1992.

Rosa - I was diagnosed only when I was 42 years old, unfortunately given that I also suffered from severe anaemia in some periods of my life, the doctors linked my abnormal fatigue and my extreme weakness to this anaemia and they didn't investigate deeper.

Chiara - For me it took 42 years; for our son, he was sick from the age of 12 and he was diagnosed at 17, so it took 5 years.

How does this disease affect you?

Fabio - I went to the gym three times a week, loved to ride my mountain bike in my city (Padova, not so far from Venice). I loved electronic music and meeting friends for a drink. Now I developed hyper sensory sensitivity due to noise and temperature. I never get warm in the winter period; I can't stand high temperatures and humidity in summer. I can't stay away more than a couple of hours from my home since I need to go to bed every 2-3 hours. My Bell scale level dropped from 80 in 1998 to 30 in year 2020. (more about Bell scale in my blog at http://bit.ly/2TZV54g, English translation available selecting UK flag on the right).

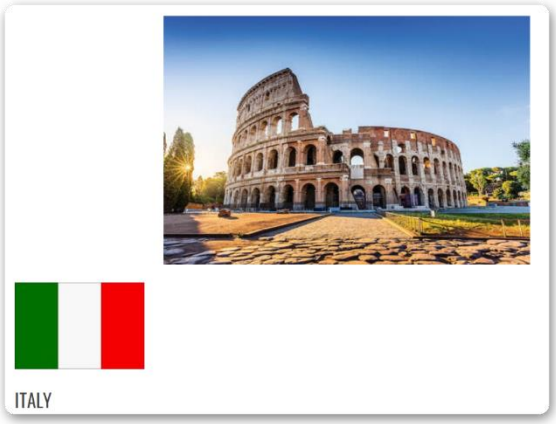
Giada - It affects me very deeply. It destroyed my life. I was severe for more or less 20 years (out of nearly 30 now), at times very severe: there were times when I needed to be spoon-fed and helped to the bathroom in my early 20s. There were years when I got out of the house no more than 4-5 times a year, only for less than half an hour and with my parents taking me out. It was torture and very isolating. On top of it all, solitude was a big problem. I had and have good friends, but I was too physically and cognitively impaired to be able to spend time with them. I could not attend University anymore. I was able to graduate just the same, but it took me 15 years to complete the 3 years I had left. I was never able to even sit while studying, in those years.

My parents just took me to take the exams, I was asked to be tested right away, and then my parents would take me back home. As much as I am constantly improving, I am nearly 50, I live with my parents who support me: I don't have a job (and couldn't handle it, save for a few hours a week, renouncing everything else – even going out for grocery shopping would be out of the question) and I've never had a personal romantic relationship.

Rosa - Some days I am bedridden for many hours of the day, as if I had a high fever, without strength and without the possibility of performing even the simplest activities such as taking the dog out or preparing a meal.

Chiara - It ruined my life because it mainly hit my head and I had absurd pains 24/7 for 360 days a year, I lost my job. I've raised three children, and one was already grown up, but somehow I was much luckier than Valerio who, being sick from the age of 12. He couldn't finish his studies, apart from the eighth grade and 3rd year of high school without being able to reach the diploma; he doesn't even have a driving license anymore.

For him it was much harder because he was hit from the muscle-skeletal point of view, so absurd pains, from the point of view of concentration and also from the point of view of strength. CFS ME has reduced his autonomy by 80 - 100% while it has limited to 60-70%. Luckily I have always had my husband close to me, otherwise I wouldn't have been able to do anything on my own, because in addition to the pain there was also tiredness, but the doctors blamed it all on the headaches. In our case it was all caused by a virus."



Mike Harley

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

Part 2 to be published in the June 2020-issue

(read more http://bit.ly/2UyYp5M)

The Universe Within ME

Every day is a challenge

I tilted my neck back slightly to rest my head on the back of the bench and soaked up the watery February sun. It seeped rapidly through my body, running down my arteries and veins like liquid mercury. I stood up and passed out.

I remember the school calling my mother – an unheard-of occurrence. I remember my father coming to collect me. I remember I was 15 years old. I remember I never went back.

Now it's 2020 and that was 50 years ago. I was due to take my incredibly important exams, go into the sixth form and then to university, like my sister before me. A life just beginning ended that day.

At that time no allowances were made for illness. 'Glandular Fever? You should be over it by now.' I wasn't allowed to go back to school – no concessions there. After five years of hard slog at grammar school, I had no review of my work or estimated results, despite the fact that at that time there was nothing available for those shameful people who had no O-levels under their belts. So I left school with no exams, no prospects, no future, no self-worth, no energy and no hope.

I also had no ability to study or work. There were no benefits, no support groups, no diagnosis, no treatment, no empathy, no internet and no cure. I was isolated, alone and bad. Very bad. Because there was 'nothing' wrong with me. Nothing.

My body had changed and I was suddenly fat. My dad used to say I changed shape overnight, which I did, and I never changed back. I used to play sport at school: hockey, tennis and athletics. I used to swim. At weekends I rode horses and mucked out stables. I had just begun to meet up with friends after school. We would go to the youth club, play music, dance, then dance some more and meet boys. Now I sat in an armchair and got fatter and 'lazier'.

My parents in despair sent me back to my GP. 'There's nothing wrong with you,' he said sternly. And I believed him. So did everyone else. I was sooo bad.

He sent me to the local mental hospital. I had to catch the bus on my own. It was ten miles away up a steep hill – I had to walk up that hill. Inside was Victorian and dark and scary and people wandered the corridors muttering and dribbling. I had to see a psychologist. I went six times and it nearly killed me. At the end, the psychologist said she did not believe I was mentally ill; I can never thank her enough. I believed her although no one else did and nothing changed.

My dad had lung cancer. He was properly ill, not like me. I adored him; he was worried about me and I felt bad. He died and I was still alive, in theory.

From that day sitting on the bench until today, every day has been a challenge. It took nearly 35 years before I realised, through the internet, that there were other people out there like me. I was always told I was odd, an enigma, mentally challenged, lazy, pathetic, different, overly dramatic, frustrating and bad. And that was from the medical profession. I was a leper to the medics and subsequently was sent to my own 'island' to rot.

And from that island I watched the world go by in boats. They were having fun, the people on those boats. They were sunbathing and singing, working, dancing and seeing the world.

I saw them swing through the sixties and rock through the seventies. I watched as they got fit in the eighties and banked their money in the nineties. I smiled as they were naughty in the noughties and then got confused in the teens. I witnessed it all. Sometimes I tried to join them. I paddled my tiny raft out to meet them, climbing the waves till I was sick, dragged down by lead weights round my ankles and arms, crushed by the heat of the sun, and drenched by the relentless rain. My throat would swell and I would sweat with the fatigue and the people in the boats would laugh and shout, 'Come join us, put some effort into it, you're not even trying, you will enjoy it when you get here.' But they didn't help me, because of course, there was nothing wrong with me. Nothing. I was just bad and very lazy.

Sometimes I got aboard the boat. But I didn't enjoy it. I endured it. I collapsed on that deck, feeling the nauseating swell of the sea and the atomic light from the sun, and their laughter stabbed my ears like the drill of the dentist pressing on a nerve. I longed to join in but longed more to get back to my island. Catch-22…

And yet as the years went by, I began to notice storm clouds over the boats. When I peered through the portholes I saw my friends arguing and crying. Some got divorced, some got ill and died, some grieved the loss of a partner (or worse their children) and some jumped overboard. Some got anxious and some got rich, but they all struggled. Some drank too much, some took drugs. Some travelled but then came home. In the end, they all felt their ultimate aloneness.

And I realised that life in the boat was a fantasy that I had mistakenly thought was true, because I was so young when I got sick, I knew nothing of the world except for Love Story and Disney.

It turns out that even people with good health find themselves isolated, frustrated, not good enough, frightened and grieving. Maybe not all the time when they are drunkenly distracted by the orchestra but definitely when they hit that iceberg. No one can save them or any of us; we have to find that safe place, our worthiness, within us.

So I am not bad and I am not mad. And neither are they and neither are you. You who suffer this hideous dysfunctional, unrecognised, unacknowledged illness called M.E. I want you to know that you are unwell and life is extra extra challenging for you every day. And now I know.

This is not my fault. I have tried harder to live this life than any hero who climbs a mountain, or rows the Atlantic, or wins a gold medal at the Olympics, or gains a PhD, and so have you. Ours is an invisible battle which we can never win but we can be here, living our best lives. Feeling the love when we can and the pain when we can't. An enforced meditation, yes, but maybe a route to the truth? The world is a distraction from that truth and it catches up with you, no matter who you are. At some point we all have to face our vulnerability and our mortality and make peace with it. Ours is definitely the road less travelled but my God, we are strong.

We are all heroes.

Amanda J. Charlton amandacarrollrainbow@hotmail.com

Source: ME Support http://bit.ly/2IxMf8o

‘They Dont Know The Reality’

Corina Duyn had to open a window in her home to speak to a general election candidate – she could not get to the door because she is disabled. **Corina**, who lives in Lismore, Co Waterford, went from being a self-employed artist to needing help with her most basic needs. After two years of pleading with the HSE's disability services, she can now leave her home with the support of a personal assistant twice a week.

“Candidates in the general election should listen to people like me. They don't know the reality of living with a disability,” said **Corina**.

She has lived with myalgic encephalomyelitis (ME) for over 20 years, spending three weeks in a nursing home in 2018 because she did not have enough home care to keep her safe. “My carer used to only come on weekdays so over Christmas and the New Year I only had four days' care.”

Her GP, who visited her after Christmas and found she could not dress herself, arranged for her to go to a nursing home. When a seven-day home care package was arranged **Corina** was allowed home again but she could not go out without a personal assistant. **Corina** was assessed for a personal assistant last October but only found out just before Christmas that she had been successful.

Since last week two and a half hours of my home care package are called personal assistant hours. I now have a personal assistant but nothing has really changed because the hours have been given to my main carer. “So it took two years to change the label from carer to personal assistant and now I can go outside but only for two and a half hours a week.”

Corina is a member of ME Advocates Ireland (MEAI), a voluntary group that wants to improve conditions for ME patients. “I couldn't give up my fight with the health service because I am fighting for other people who have found themselves in the same ridiculous situation as me.”

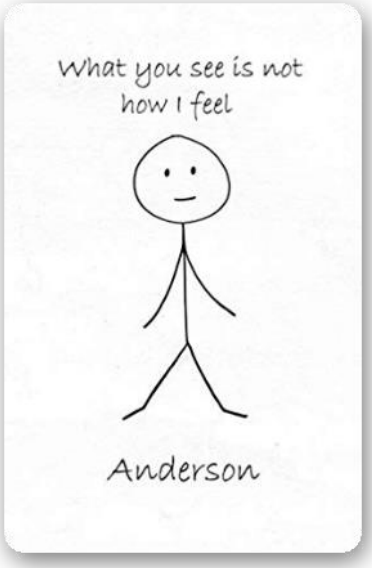
Corina was born in Holland where she trained as a nurse and social care worker before moving to Ireland in 1990. In June 1998 while applying for an art therapy course in the Crawford College of Art and Design in Cork, **Corina** was taken to hospital with suspected meningitis. A diagnosis of ME was confirmed three months later.

Corina, who will be 58 years old in March, said her creative life had kept her sane but even that is a struggle now.

“These days I spend more time thinking about what I want to do rather than doing it because I have to pay people to help me work at home.”

Source: **Evelyn Ring**, Irish Examiner Reporter http://bit.ly/2TxEDJs

What You See is Not How I Feel



The little ME book

What You See is Not How I Feel is a visually simple overview of how living with Myalgic Encephalomyelitis (CFS) feels.

It opens conversation, clears misperceptions, and encourages understanding rather than judgment. Appropriate for children, adults, and professionals.

Author: **D. Anderson**
Paperback: 978-0-2288-1968-4
Email: whatyouseebooks@gmail.com
Hardcover: 978-0-2288-1969-1
Genre: Health EBOOK: 978-0-2288-1970-7 Amazon
Search: "What You See is Not How I Feel" (**Anderson**)

About the Author

Motivated by five plus years of judgment for not appearing disabled enough, Anderson wrote this book as a simple visual tool to make clear that while appearing normal, living with Myalgic Encephalomyelitis is a life-changing and controlling disease with a complex combination and fluctuation of symptoms that cannot be "seen."

Adjusting to change, letting go of control, focusing on well-being, practicing yoga, and simply trusting and accepting what is, has been a profound learning experience for Anderson.

Excerpt From The Cover

"I went way past my energy limit today. At 3:30 pm my head is screaming with loud ringing in my ears. My feet and calves are tingling and burning; there is a sense of tight bands on my ankles. Sitting at the computer, I feel like I'm being tipped backward in my chair. My head starts dropping back, I jerk it upright. I should be lying down, but needed to write this. I will pay for it tomorrow."

"**Anderson**'s book is a must read for anyone that knows or works with people with Myalgic Encephalomyelitis. It brilliantly illustrates and explains her experience in a way that one is able to comprehend what is experienced daily."

Dr. Pamela Kryskow, **MD**, **CCFP**, **Pain Specialist**
"In this deceptively simple and compassionate book, **Anderson** has managed to make visible the invisible realities of what people living with Chronic Fatigue (ME) live with every day. I would recommend this book to all people living with CFS (ME), their families, friends and health professionals. For those living with CFS (ME) it will feel like a huge relief to finally have someone put into words what are often wordless and difficult. For everyone else it will open your eyes and hearts to how CFS (ME) robs a person of their life and vitality."

Eva Dicasmirro, **Physiotherapist** and **Somatic Psychotherapist**, specializing in trauma resolution and chronic illness

What inspired you to write about your story?
I wrote and illustrated this book because I have been doubted in having the disease. Looking on, I seem normal. This is an unseen illness. Insurance investigators can only see the outside, but not the full effects of the disease.

In frustration, I sat down to draw and write something simple enough to be understood, but still convey the complexity of the illness.

Why did you decide to publish?
I decided to publish when I realized that this book not only made explaining easier for me, but could be useful for others trying to explain the illness they are living with. The book is simple enough that it can be used with children and quickly informs adults.

What do you hope readers will get from reading your book? Empathy and understanding.

This is a deeply personal story for you, what did you learn about yourself through the writing process?
That telling my story is part of my own healing process. It has been both validating and cathartic.

What is a piece of wisdom you would like to impart with your readers?
There is always more than meets the eye, especially when it comes to health.

All info: www.whatyouseebooks.wordpress.com

A Girl Behind Dark Glasses

A Girl behind Dark Glasses – **Jessica Taylor-Bearman**

Jessica's announcement and request:
"*The final for The People's Book Prize is open! If you could vote for A Girl Behind Dark Glasses, I would be eternally grateful. If you have already voted a few months ago, you can vote once more. I really feel that by using the platform of The People's Book Prize, we can create noise around the subject of severe M.E. and get understanding. Please share this far and wide. Together our voices are louder.*"

To vote: http://bit.ly/3aN5c31

Synopsis

From a darkened world, bound by four walls, a young woman called Jessica tells the tale of her battle against the M. E. Monster. The severest form of a neuroimmune disease called Myalgic Encephalomyelitis went to war with her at just 15 years old. From beneath her dark glasses, **Jessica** glimpses a world far different from the one she remembers as a teenage schoolgirl. This true story follows her path as she ends up living in a hospital for years with tubes keeping her alive.

This harrowing story follows the highs and lows of the disease and being hospitalised, captured through her voice-activated technology diary called "Bug" that enables her to fulfil her dream of one day becoming an author.

It provides a raw, real-time honesty to the story that would be impossible to capture in hindsight.

Authors Biography

At the age of 15, she became acutely unwell with an illness called Myalgic Encephalomyletis (M.E). She was continuously hospitalised from 2006-2010, suffering with the most severe form of the condition. This included her being bedridden, unable to move, speak, eat and more.

She began to write in her mind, and when finally able to speak again, she began to write through her audio diary 'Bug'. **Jessica** released her debut bestselling book 'A Girl Behind Dark Glasses' in 2017.

Unrest - 2019 Media Impact Award – Jennifer Brea

Jennifer Brea has been selected to be the 2019 recipient of the Invisible Disabilities Association's first ever Media Impact Award.

The Invisible Disabilities® Association (IDA) is a 501(c)3 nonprofit. IDA is about believing. We believe you! The frequently invisible nature of illness and pain may lead to disbelief about that illness or pain by those surrounding the person who lives daily with invisible disabilities. This disbelief can lead to misunderstandings, rejection by friends, family and heath care providers. It may also lead to accusations of laziness or faking an illness. We are passionate about providing awareness that invisible illness, pain and disabilities are very real! Our mission is to encourage, educate and connect people and organizations touched by illness, pain and disability around the globe. Envision with us, a world where people living with illness, pain and disability will be Invisible No More

Jennifer has been chosen based upon her incredible passion and determination to tell the journey of her personal story of illness and to bring visibility to the millions of people living with ME – Myalgic Encephalomyelitis and Chronic Fatigue Syndrome around the world, as the Director and Producer of the international award-winning documentary film, **Unrest**. In addition, IDA applauds her continued strength and vision through the co-founding of the global grass roots network organization, #MEAction.

Jennifer is an independent documentary filmmaker based in Los Angeles. She has an AB from Princeton University and was a PhD student at Harvard until sudden illness left her bedridden. In the aftermath, she rediscovered her first love, film. Her Sundance award-winning feature documentary, **Unrest**, has screened in over 30 countries and had its US national broadcast on PBS's Independent Lens. She is also co-creator of Unrest VR, winner of the Sheffield Doc|Fest Alternate Realities Award. An activist for people with disabilities and chronic illness, she co-founded a global advocacy network, #MEAction and is a TED Talker.

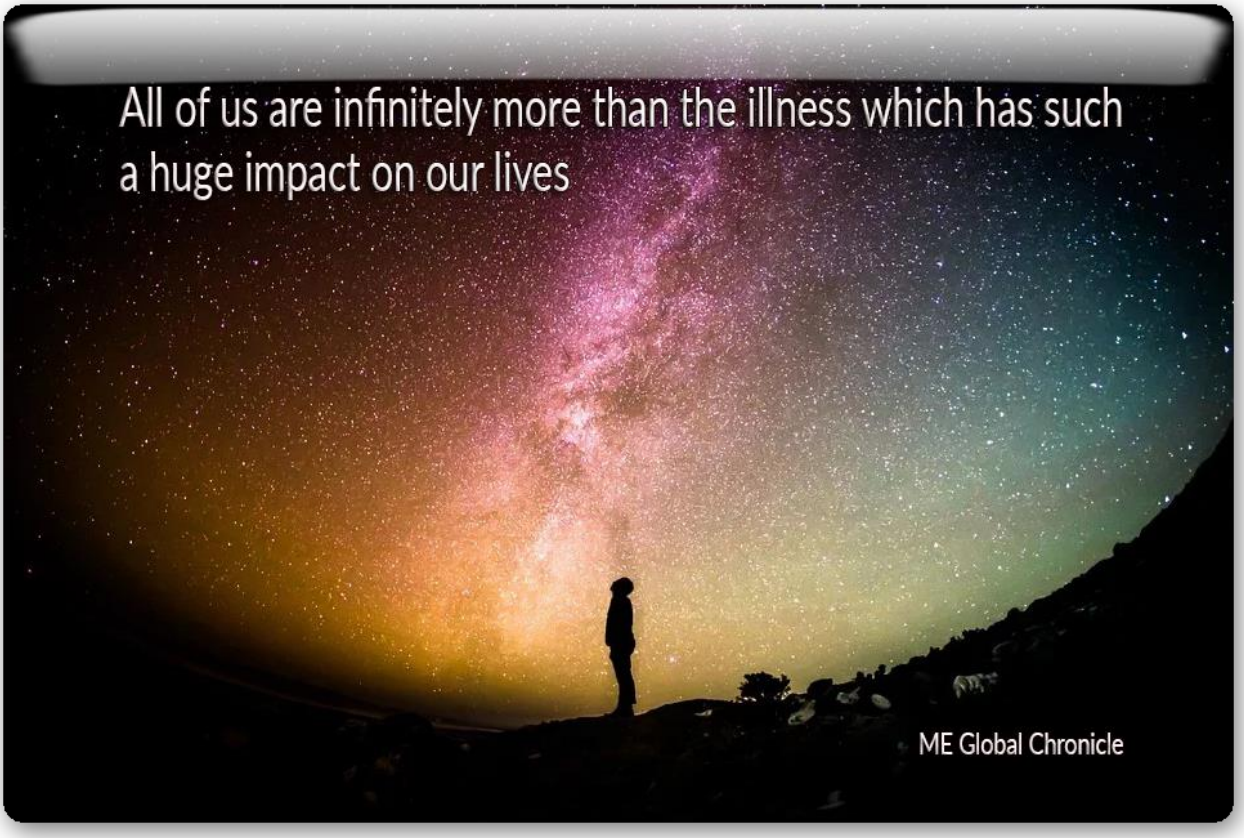
Unrest – The Film

Jennifer's Sundance award-winning documentary, **Unrest**, is a personal journey from patient to advocate to storyteller. **Jennifer** is twenty-eight years-old, working on her PhD at Harvard, and months away from marrying the love of her life when a mysterious fever leaves her bedridden. When doctors tell her it's "all in her head," she picks up her camera as an act of defiance and brings us into a hidden world of millions that medicine abandoned.

In this story of love and loss, newlyweds **Jennifer** and **Omar** search for answers as they face unexpected obstacles with great heart. Often confined by her illness to the private space of her bed, **Jennifer** connects with others around the globe. Like a modern-day Odysseus, she travels by Skype into a forgotten community, crafting intimate portraits of four other families suffering similarly.

Jennifer's wonderfully honest and humane portrayal asks us to rethink the stigma around an illness that affects millions. **Unrest** is a vulnerable and eloquent personal documentary that is sure to hit closer to home than many could imagine.

Source: http://bit.ly/2VX78C3



Chronic Fatigue Syndrome: Living With an Invisible Illness

Lorna Bryson, 25, suffers from Myalgic Encephalomyelitis (ME) also known as chronic fatigue syndrome.

The illness means she has a low immune system, gets headaches, sore muscles and joints, and needs at least 12 hours sleep every night.

Doctors didn't believe there was anything wrong with Lorna growing up as she looks visibly healthy, but the debilitating illness means she's unable to work and relies heavily on her parents.

Watch the video here: https://bbc.in/2TZKqqg

Video journalist: **Emily McGarvey**

Dialogues for a Neglected Illness

Dialogues for a Neglected Illness – or Dialogues for ME/CFS (http://www.dialogues-mecfs.co.uk) is a three year project being made with an award from the Wellcome Public Engagement Fund 2018. It is produced by **Natalie Boulton** and **Josh Biggs**, who made Voices from the Shadows together in 2011.

Dialogues for ME/CFS is a work 'in progress' and videos and material will be made and added over the next 12-18 months. It will consist of a website at http://www.dialogues-mecfs.co.uk with about a dozen new short videos, accompanied by links to existing educational materials and references.

The videos will address different aspects of the disease, probably including –

- Diagnosis and various management and treatment issues (GET, PEM, Pacing),
- Severe ME (including issues with hospital admissions) and the support doctors can provide,
- Key symptoms as described by patients (mostly from the UK ME/CFS Biobank) in their own words, including short and long term experiences and differing severities,
- Some ME patient advocates' concerns,
- The broader historical, social, medical and cultural context for the disease.

It will create a resource which patients can use to help doctors, other health professionals, educators and research professionals, as well as families and friends, understand more about this disease and the issues involved. Patients and carers may also learn from some of the videos, as I have as a carer, in making them.

The project will include an event organised and hosted by the project consultants from the CureME and Biobankteam, at the London School of Hygiene and Tropical Medicine, in May 2021 – **Dr Luis Nacul**, **Dr Eliana Lacerda**, **Caroline Kingdon** and **Jack Butterworth**.

The first two videos on Understanding Graded Exercise Therapy were screened at the Hope4ME&Fibro conference in Belfast in September and have already been used in providing presentations for GPs.

The next video to be finished, Understanding Post Exertional Malaise, was shown at the CMRC conference in Bristol this March. This video was very well received by the audience including **Prof Steven Holgate** and **Prof Chris Ponting**, and a couple of researchers in a research meeting are reported to have said that it had really helped them to understand about PEM.

There is also a 6 min video, a brief guide to PEM, suitable for very busy professionals and medical students and it is included in **Dr Nina Muirhead**'s medical student training materials.

The last of the videos to be completed, although the first to have been started is An Introduction to ME/CFS. I hope it will help some of those doctors who 'don't really believe in ME' to feel it is time for them to change their minds!!! It seems from **Dr Nina Muirhead**'s presentation at the CMRC conference that there are still an unbelievably large number of them.

I am extremely grateful to all the patients, doctors and researchers who have made every effort to help and continue to help us with this project, in very many different ways. Although we won't be able to do any more filming for a while due to Covid19, there is enough material for us to continue to work with for now, so we can make some more videos which can be updated at a later date if necessary.

Natalie Boulton

Solve M.E. Announces 2020 ME/CFS Advocacy Week Virtual Transition in Response to Covid-19

In the video clip below, Solve M.E. Director of Advocacy and Community Engagement Emily Taylor explains her decision to make 2020 ME/CFS Advocacy Week a Virtual Event - http://bit.ly/2Wg5Ou9

Solve M.E. Advocacy Week activities this April in Washington, D.C., will be transitioning to entirely remote formats and our team will be cancelling in-person events to protect and preserve the health of our ME/CFS community.

Our keystone event, ME/CFS Advocacy Day, brings our ME/CFS research and advocacy community face-to-face with members of Congress. We are pleased to announce that Advocacy Day congressional meetings will STILL take place on Tuesday, April 21 by remote online and phone systems.

What does this mean for you?

- If you are already registered to attend, we recommend you cancel your travel and hotel arrangements. You will need to re-register using a new system (coming soon!).
- If you were already unable to travel to DC, this is great news! You can participate remotely by registering in our new upcoming system.
- Our EmPOWER M.E. event, "Navigating Public and Private Disability Insurance," will still take place, but at a different time. Sign up to Livestream the EmPOWER M.E. from your computer or tablet at: http://bit.ly/3b3psxG
- The "Solving M.E. Together" Advocacy training will be transitioned to an online Webinar at a new time. A registration link will be emailed in the coming weeks.

Stay tuned for more updates as we transition to online events. If you have any questions, please email our team at SolveCFS@SolveCFS.org
For the latest news and updates, visit http://bit.ly/33meNeM

With the President's signature on H.R. 1865 and H.R. 1158, the 2020 federal budget is now finalized – totaling a record-breaking $2.75 trillion. Here's what the 2020 budget means for ME/CFS:

- $350 Million Defense Research Program now open for ME/CFS!
- The Clock is Ticking for HHS to Act on ME/CFS
- Advocates Preserve $5.4 Million for CDC Research and Education Programs
- Congress Issues ME/CFS Direction to NIH Leadership
- Senate Unanimously Passes ME/CFS Resolution
- PCORI Extended for 10 years with $3.3 Billion

To read detailed information about each of these items, click here: https://solvecfs.org/victory-six-major-federal-wins-for-me-cfs

Submitted by **Karman Kregloe**

When Coping Is Too Much

Life has been painful, of late.

Circumstances have brought a profound awareness of my limitations. The ongoing serious illness of someone I love. The approaching first anniversary of my father's death; the fact that I was too ill to visit the intensive care unit where he spent the final month of his life.

After thirty years, I thought there were few ways left for my illness to hurt me. Now I know the pain of enforced absence during a loved one's suffering. No other illness-related loss has cut quite as deeply as this, I think. It can be hard to maintain my own sense of worth when reminded of my inability to convert love into physical presence and practical assistance.

At times of additional emotional strain, such as this, the usual day to day limitations become harder to bear. My complete dependence on others; the lack of even basic freedom; the need to spend hours lying in darkness just to maintain a small level of functioning: suddenly I feel the true strain of all these restrictions. It amazes me how I can flip from a state where my illness is bearable, to one where its weight chokes me afresh. Or perhaps my amazement should be reserved for the fact that it ever feels bearable at all.

The greatest challenge at times like this is how to deal with emotional pain when severely incapacitated. For the healthy world, distraction and activity are the coping mechanisms of choice. For those of us denied any such luxury, strong emotions take on a whole extra dimension. There is no opportunity for escape or for real release: the pain must be stared in the face and felt in full.

At times of deep distress, I have an abiding sense that I ought to be able to wrestle my pain to the ground and bring it under control. I respond to others' suffering with patience and compassion, yet struggle to extend the same kindness to myself.

I fear that in crumbling, I am failing. That in allowing myself to grieve, I am somehow taking a step backwards. Anxiety tells me that I am not appreciating the good in my life, and that it will therefore be taken away from me. (By what cruel twist of logic is gratitude the only acceptable response to lifelong, severe illness?) My instinct is to want to put everything back in order as quickly as possible; to tidy up the emotional chaos and return to a calmer, more buoyant me. The more I struggle to do it, the worse I feel about myself.

But this week, on a particularly tough day, I reached a new understanding. These times of grieving are not, in fact, a disruption in my ability to cope: they are instead a vital part of it. The release of emotion through mourning is what allows space for my strength to grow. When I fight my need to grieve, I create tension and a great sense of failure. In allowing it to be, I acknowledge that I am only human, and give myself room to heal.

I could have written this as a piece on managing emotion, complete with tips on boosting mood and suggestions of ways to feel more positive. Instead it seemed important to approach it from a different angle. To say to myself, and to anyone struggling similarly, that sometimes it's ok not to be ok. There are times when the pain, like an unwelcome guest, cannot be forced to leave and must instead, for a time, simply be lived with.

Although I tend to see my illness grief as a negative force to be banished, in reality it is an important part of my true self. My tears and anger represent my belief that there can and should be more than this. Acceptance and optimism have their place, but so too do rage and a refusal to accept. At the core of my anguish lies not defeat but my fight itself. My grief is my scream at the world; my rejection of my suffering; and a promise to myself that my spirit will not be broken.

Naomi
Source: A Life Hidden http://bit.ly/2WqKrGF

Greetings from ME International!

We are in the process of updating our website and would love for you to check it out. Lots of great information on ME history, ME criteria and a copy of our newsletter which is filled with great information. See our recent blog about ME and Coronavirus. Here is a link to our main page:
https://www.me-international.org/

Because of the Coronavirus outbreak, we would like you to check out our cheat sheets, especially the one on going to the emergency room which includes information about patients may not show a fever when ill. This issue could impact patients having access to testing. Here is a link to that cheat sheet: https://www.me-international.org/emergency-room-info-for-me-patients.html

We also have setup our social media sites on FB, Twitter, Linkedin and Pinterest (see links below). We would love for you to join us on any of those sites. Our Facebook page contains the latest information on the world of ME. We would also like you to join us as a member and become involved in promoting ME to the world.

Connect to us here: https://www.me-international.org/connect.html

We hope all of you are taking it easy and keeping up to date on the latest regarding the virus. This is a very sad time for our world. We wish you the best and hope you all stay as well as possible. Please contact us if we can be of any help. Our main email is admin@ME-International.org

Pam Lutey
Marketing Director

Links to connect to ME-International:
FB: https://www.facebook.com/groups/418905828754500/?ref=group_header
Linkedin: https://www.linkedin.com/in/pam-lutey-96b284196/
Pinterest: https://www.pinterest.com/meinternationalorg/
Twitter: https://twitter.com/ME_Intl

Almost of Epic Proportions

A few weeks ago I made it to the beach. This adventure is almost of epic proportions.

During the past year I rarely left my home, only on very few occasions have I left my town. Once in March, twice for Physio during the summer.

The beach is only half hour away. I longed to see it. With dear friend Pascale, we booked an apartment for two nights as close to the seaside as was possible. It was all a big adventure, and one I wasn't sure I could manage.

After the half hour journey I had to rest. My friend rearranged the furniture in our 'retreat' so we could both have a couch and see the sea.

There is only a lawn between the apartment and the beach. Yet, getting to the actual beach was not within my reach that first day.

The following morning the skies were blue. I had assistance to wrap me up in as many layers as was possible. We drove/walked over the grass to the edge. The beach close, and yet so far.

Pascale had found a little cove the day before. I got out of my chair, slid down the grass, and down onto the beach. I made it! I was grateful. I was sitting on the the beach. The first time in a few years.

I cried.

Such a simple task, which takes such an enormous effort. As I was in pain sitting unsupported, we dismantled parts of my wheelchair. So I sat on my cushion, and had the backrest leaning against the bank. My feet were support with little mounds of sand. Joy so close to tears.

The pain from this adventure has not yet dissolved, three weeks later. But I am forever grateful to have been on the beach and to know I can leave my home, although it comes with payback...

Corina Duyn
Source: http://bit.ly/3cNGBNz

In Memoriam: Cindy Siegel Shepler

Cindy Siegel Shepler, 62, succumbed to a myriad of chronic diseases on December 16, 2019.

Cindy was a pioneer throughout her life - the first in the history of her family to be a bat mitzvah, unusual for Jewish girls at the time; a member of the first graduating class at Laurel High School; took a gap year, rare at the time, before moving to the West Coast for College; was an early devotee of Earth Shoes, waterbeds, vegetarianism and the raw foods movement; established and operated possibly the first juice bar in San Francisco; participated in the first San Francisco AIDS Walk in 1987; helped to co-found the first Knoxville Humane Society's benefit "Bark in the Park" in 1995 as well as the first "Martini Party" in 1998 to benefit the Knoxville Opera Guild.

Cindy was a summa cum laude graduate of San Francisco State University, followed by a brief but successful career as an Account Executive with Cigna. Her ambition was to become a financially independent career woman, with the help of her made-for-sales personality. This dream was derailed by her declining health, resulting in a move back home to Knoxville in 1993. She remained productive and involved with her volunteer work, and also decided to learn how to play duplicate bridge, a very competitive card game. In addition to becoming an ACBL Silver Life Master, she also met her future husband David at a bridge game.

One of Cindy's serious ailments was myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), which she struggled with for five decades. Even though she was low on energy most of the time, she became a zealous advocate for all who suffered from this disease as well as other health issues. She was truly a "citizen scientist" delving deep into research and theory and was a staunch advocate, leading efforts to raise awareness and increase government funding for research. She became a Community Ambassador for the Open Medicine Foundation, a non-profit that funds research for ME/CFS and other chronic diseases. She organized a trifecta of awareness in Knoxville in the form of a mayoral ME/CFS Proclamation, a ME/CFS City Council Resolution, and the annual blue lighting of the Henley Street Bridge.

Typical of **Cindy**'s proactivity, when she developed a rare genetic skin disorder at age 51 she started a Facebook group known as the Hailey-Hailey Disease Worldwide Support Group. People with this condition often have painful, debilitating skin flares along with depression, and she wanted them to have world-wide 24/7 support. She also advocated for the legalization of medical cannabis and death with dignity.

These roles hardly define her. She loved cats! Having decided not to have children due to her health problems, her beloved **Mocha** and little **Zelda** received her motherly love. Someone once gave her a bumper sticker that said, "In my next life I want to be **Cindy**'s cat." They truly were her little soulmates. Listening to music was also one of her great pleasures. She would record TV shows The Voice and Songland and replay her favorite songs over and over. Laughter and humor were her go-to medications. As a young girl she wanted to grow up and be a clown. If you ever had the experience of hearing her laugh - the uncontrollable, no holds barred, hard-to-catch-her-breath, contagious laugh, then lucky you - you have experienced a piece of heaven.

The family asks that to honor **Cindy**'s memory you consider a donation to the Open Medicine Foundation (https://www.omf.ngo/#donatenow) , or to The Survivor Mitzvah Project, or to Rare Genomics Institute. A celebration of **Cindy**'s life will be held by close family members and good friends. Memories and condolences may be shared at https://www.kudoboard.com/boards/IwrdIYIV

Published in Knoxville News Sentinel from Feb. 21 to Feb. 23, 2020

In Memoriam: Dr. Marcie Zinn

We are deeply saddened by the sudden death of **Marcie Zinn**, PhD, who was a dedicated researcher, advocate and person with myalgic encephalomyelitis (ME). **Marcie** died of sudden heart failure on Dec. 28, 2019. **Marcie** and her husband, **Mark**, founded the Neurocognitive Research Institute (NCRI), a non-profit that specializes in 3D-mapping of the brain to assess brain activity and linkage between brain regions. The neurocognitive assessments they conduct are being used for ME research, and to help people with ME win disability claims.

Marcie was diagnosed with herpes viral encephalitis in 2009, which developed into ME, and her interest turned toward using her extensive brain mapping (qEEG / LORETA imaging) and neuroscience skills for research into ME.

Leonard Jason, PhD, professor at DePaul University, who worked with **Marcie** on several important publications on ME, said **Marcie**'s presence in the field will be missed. "She produced excellent qEEG research that provided a better understanding of how disease states cause disruption to dynamic homeostatic processes, compromising feedback and regulatory mechanisms necessary for properly maintaining the central nervous system and the autonomic nervous system," **Dr. Jason** wrote. **Megan Doherty** remembered the profound moment when she received validation that ME was causing her life-altering symptoms while participating in one of the **Zinn**'s qEEG/LORETA studies at DePaul University.

"Like many of us, I spent the first few years of my illness bewildered, frustrated, scared, and gaslighted by medical professionals," **Megan** wrote. "Most people dread medical tests coming back positive, but we who have ME understand the surprising, seemingly endless, disappointment of being told, "Everything's normal, you appear to be perfectly healthy." "After countless blood tests and almost as many doctors, I found myself with electrodes attached to my head in **Marcie Zinn**'s office. I was participating in her qEEG studies at DePaul, and was terrified they wouldn't find anything. When the results came on the screen, I saw a 3D model of my brain bathed in blue, representing abnormally low brain activity. I asked **Mark**, her husband, to make sure I understood: that was me, and there was really, truly, something wrong. I started to cry. I was overwhelmed with an ambiguous relief, seeing before my eyes concrete proof that I wasn't crazy; I was just sick.

"At that moment, **Marcie** stuck her head in, and saw my vulnerability. She came in and put her hand gently on my arm. She listened, validated my feelings, and told me she understood exactly what I was going through, and what that moment represented for me. She made me feel seen, heard, and that my experience mattered. What she did was simple, but profound. **Marcie** was one of the first people who made me feel less alone with this horrible disease, and I've never forgotten that."

Marcie Zinn's Research on ME

Marcie dedicated herself to researching the neurocognitive dysfunctionality of people with ME. She was an author on the publication of 6 studies and reviews focused on ME:

- qEEG / LORETA in Assessment of Neurocognitive Impairment in a Patient with Chronic Fatigue Syndrome: A Case Report (http://bit.ly/1Tg79t9)
- Small-World Network Analysis of Cortical Connectivity in Chronic Fatigue Syndrome Using Quantitative EEG (http://bit.ly/3b0pxlr)
- Functional Neural Network Connectivity in Myalgic Encephalomyelitis (http://bit.ly/2QiQady)
- Cortical Hypoactivation During Resting EEG Suggests Central Nervous System Pathology in Patients With Chronic Fatigue Syndrome (http://bit.ly/2Qm9VAR)
- Intrinsic Functional Hypoconnectivity in Core Neurocognitive Networks Suggests Central Nervous System Pathology in Patients With Myalgic Encephalomyelitis: A Pilot Study (http://bit.ly/2TUqQNi)
- Myalgic Encephalomyelitis: Symptoms and Biomarkers (http://bit.ly/2UaKYd2)

Marcie was also an advocate for ME, participating at the #MillionsMissing demonstrations in Chicago. She also served on working groups for ME/CFS as part of the Common Data Element (CDE) Project, sponsored by the National Institutes of Health and Centers for Disease Control and Prevention.

Career in Performance Neuroscience

Dr Zinn's early research and career interests were in Performance Neuroscience and Psychology. She spent more than two decades helping pianists from preschool to concert-level overcome behavioural challenges impeding their art through better teaching practices, behaviour analysis, biofeedback and specialized techniques. Her book Healthy Piano Playing, has recently been cited as one of the top ten books for Piano Pedagogy. She founded the Musician's Stress Management company (later ArtsNova Consulting Group). Marcie has published dozens of articles and abstracts in scientific journals. View her research profile (http://bit.ly/3901SAi).

Mark has launched a GoFundME campaign to raise money for the Neurocognitive Research Institute (NCRI) in memory of Marcie. Donate (http://bit.ly/2xLD16r) to NCRI in memory of **Marcie**. (Read more (http://bit.ly/2UbumSl) about NCRI, and watch a video (http://bit.ly/2wYVr3l) about their process.)

"How can we stop ME/CFS progression?" writes **Marcie**'s husband, **Mark**. "How can we reverse symptoms and repair the damage caused by ME/CFS? Our research projects seek to answer these questions. "**Marcie** was an incredible driving force and life partner to me," writes **Mark**. "She had a heart of gold and went out of her way to touch the lives of so many people. Please help memorialize Marcie and support her work at this time… No amount is too small and every dollar is appreciated."

Source: #MEAction http://bit.ly/2x4Dd04

7. Save4Children – An Update

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

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

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

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

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

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

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

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

New way of donating

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

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

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

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

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

8. Science

CFS/ME Should Be Managed in General Practice

Diagnosis, acknowledgment and education are major steps in helping patients cope with this serious illness.

Much can be achieved with support, understanding and a personalized management plan. Practicing relaxation strategies with good breathing technique should be encouraged, as stress is an aggravating factor in any illness.

These patients are able to exercise only minimally but do not lack motivation. Exercise intolerance is a core symptom associated with the altered gene expression and mitochondrial dysfunction. The ill effects are often delayed, with prolonged recovery or relapse.

Some patients are bedridden, others can cope with low-key regular exercise. Sports people find it particularly hard to slow down to allow recovery. As symptoms of orthostatic intolerance are prominent, exercise lying down, such as swimming, may be the best type of exercise.

Gastro-intestinal symptoms are common, with sluggish movement of food through the gut and bloating discomfort. Many patients will have tried different diets but unless there is an identified food allergy or intolerance, such as gluten or lactose, the aim is for varied, balanced nutrition. Fad diets rarely have benefit, and may compromise nutrition.

Small frequent meals should be encouraged. Caffeine and alcohol can exacerbate symptoms. Minerals and vitamins are best absorbed from food, but patients will often have tried many supplements, despite little evidence of benefit.

Supplements that have been shown to be useful include Vitamin D (because of lack of daylight exposure), magnesium at bedtime to relieve pain, CoEnzyme Q10 (levels have been shown to be lower in patients than controls, inversely related to symptom severity), Zinc (inadequate zinc intake contributes to decreased NK cell function) and Vitamin B12 (cerebrospinal fluid levels of B12 may be depleted). Mega-doses of Vitamin C should be avoided as this will aggravate bowel symptoms.

Most CFS/ME patients are hypotensive, with orthostatic intolerance, possibly due to lowered blood volume and dysautonomia. Having plenty of salt (5–10 g) regularly spaced through the day can improve these symptoms. Fludrocortisone may be useful.

Women with CFS/ME outnumber men 4:1 so hormonal issues maybe involved. Many experience cyclical illness fluctuations or problems at menopause. Oestrogen has potentially positive effects in improving cerebral circulation, cognition, muscle and joint elasticity, relieving flushes and insomnia and can decrease immune overactivity. Hormonal management with contraception or hormone replacement alleviates cyclical symptoms.

Pregnancy is not contra-indicated but should be planned when health improves. Most CFS/ME patients do well in pregnancy. B12 use should probably be stopped in pregnancy as it may be associated with increased risk of autism.

For teenagers with acne, local skin preparations, antibiotics or oral contraceptives are suitable. Isotretinoin has been anecdotally associated with CFS/ME onset or relapse.

Non-restorative sleep is a feature of CFS/ME. Hypersomnia is common early in the illness. Other sleep disorders can co-exist. Sleep hygiene and maintaining a normal sleep/wake cycle is vital. A light snack at bedtime is helpful because the orexin system is faulty. Increasing glucose levels will lower orexin thereby improving sleep. Bedtime stimulation with electronic devices should be avoided. Some patients try natural approaches to sleep management, including 5HTP, tart cherry or chamomile. Prescribed medication is often needed.

Dr. Ros Vallings

As part of a guest editorial in the Journal of Primary Health Care, Volume 11 Number 4 2019 https://doi.org/10.1071/HCv11n4_ED2

Transcriptomics: Revisiting the Genomes of Herpesviruses

Combining integrative genomics and systems biology approaches has revealed new and conserved features in the genome of human herpesvirus 6.

Herpesviruses cause a range of human diseases but many factors complicate the efforts made to precisely map the size and origin of RNA transcripts coded by these pathogens. For example, some mRNAs can code for more than one protein, coding sequences may overlap with each other, and the genes that are expressed may change depending on cell types or stages in the viral cycle. Moreover, the level of expression can greatly vary from gene to gene, which makes it difficult to distinguish between rare viral transcripts and other genetic products that accumulate in infected cells and during viral replication. In fact, in most herpesviruses, the majority of the genome is transcribed to some degree, yet only the most highly expressed or genomically isolated units are readily detectable.

Several new techniques have allowed researchers to bypass these problems to better annotate the genomes of herpesviruses. A tailored RNA sequencing method called cRNA-Seq, which enriches for the 5' ends of RNA transcripts, has allowed the mapping of transcription start sites; in parallel, ribosome profiling (Ribo-Seq) has helped to highlight translational start sites. Combined, these approaches have revealed dozens to hundreds of new genes in herpesviruses such as the human cytomegalovirus (**Stern-Ginossar et al.**, 2012) and the Kaposi's sarcoma-associated herpesvirus (**Arias et al.**, 2014). When paired with long-read sequencing platforms (which provide additional information about the 3' ends of transcripts), the new methods have also led to a better understanding of a number of pathogens in the herpes family. Now, in eLife, **Noam Stern-Ginossar** and colleagues at the Weizmann Institute of Science and the Hebrew University Hadassah Medical School – including **Yaara Finkel** as first author – report new insights into human herpesvirus 6A and 6B (**Finkel et al.**, 2020).

The results help to correct and complement previous textbook genome annotations for herpesviruses. Due to the technical limitations of the time, the exact beginnings of many transcripts and coding sequences were assigned a priori, and inclusion into published gene lists relied on rather conservative criteria. For instance, a sequence was classified as an open reading frame (the part of a genetic sequence that can potentially be translated) if it had more than 100 amino acids and started with an AUG codon. Instead, **Finkel et al.** demonstrate that roughly one-third of open reading frames in human herpesvirus 6A and 6B contain alternative start codons, which are also used by eukaryotes and other herpesviruses (**Kearse** and **Wilusz**, 2017; **Arias et al.**, 2014). For instance, strains of human cytomegalovirus can have different start codons for a given gene, which may influence biological properties (**Brondke et al.**, 2007); such questions can now be investigated in herpesvirus 6A and 6B .

Another exciting finding is the identification of hundreds of short, internal or upstream open reading frames. The proteins encoded by many of these sequences are likely to be too small to have direct functions. However, some of these short open reading frames are close to (or overlap with) longer coding sequences, suggesting that they may regulate translation – particularly during the later stage of viral gene expression, when homeostasis in the host cells is most disrupted. **Finkel et al.** observed that several of these open reading frames are also transcribed in human cytomegalovirus, indicating important conserved roles across the family of viruses that herpesvirus 6A and 6B belong to.

Taking a closer look at the genomes of human herpesviruses 6.

Finkel et al. have used a combination of techniques to reannotate the genomes of human herpesviruses 6A and 6B. They have identified new open reading frames.

Combining several methods that can pinpoint both translational and transcriptional start sites – as **Finkel et al.** did – is particularly important because modern sequencing protocols are sensitive enough to identify rare transcription events, but they cannot distinguish between 'real' transcriptional units and biological artifacts. Whole-genome conclusions based on one technique or method of analysis are heavily influenced by experimental noise, technical limitations and even the specific algorithm used to interpret the data. For instance, estimates of the exact number of transcriptional start sites in human cytomegalovirus vary by thousands between studies that use different methods (**Stern-Ginossar et al.**, 2012; **Parida et al.**, 2019); in herpes simplex virus, these numbers can vary by over six-fold (**Tombácz et al.**, 2019; **Depledge et al.**, 2019).

While our appreciation of the coding capacity of pathogens increases, efforts must be made to integrate newly identified gene products into already established nomenclatures. The first waves of new annotations using high-throughput techniques will probably be revised as sequencing technology and analysis techniques improve, and the results are validated in the lab.

In particular, new algorithms that can better distinguish signal-to-noise values could help to identify hundreds of additional peptides in a second revision of the human cytomegalovirus genome (**Erhard et al.**, 2018). As our ability to sequence deeper develops, multifaceted studies such as the one by **Finkel et al.** will provide an excellent framework to help distinguish between rare functional events and technical noise when re-examining herpesvirus genome annotations.

Bhupesh K Prusty, **Adam W Whisnant**

Source: https://elifesciences.org/articles/54037

Cell-Based Blood Biomarkers for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Abstract

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a devastating illness whose biomedical basis is now beginning to be elucidated. We reported previously that, after recovery from frozen storage, lymphocytes (peripheral blood mononuclear cells, PBMCs) from ME/CFS patients die faster in culture medium than those from healthy controls. We also found that lymphoblastoid cell lines (lymphoblasts) derived from these PBMCs exhibit multiple abnormalities in mitochondrial respiratory function and signalling activity by the cellular stress-sensing kinase Target Of Rapamycin Complex 1 (TORC1).

These differences were correlated with disease severity, as measured by the Richardson and Lidbury weighted standing test. The clarity of the differences between these cells derived from ME/CFS patient blood and those from healthy controls suggested that they may provide useful biomarkers for ME/CFS. Here, we report a preliminary investigation into that possibility using a variety of analytical classification tools, including linear discriminant analysis, logistic regression and receiver operating characteristic (ROC) curve analysis.

We found that results from three different tests—lymphocyte death rate, mitochondrial respiratory function and TORC1 activity—could each individually serve as a biomarker with better than 90% sensitivity but only modest specificity vís a vís healthy controls. However, in combination, they provided a cell-based biomarker with sensitivity and specificity approaching 100% in our sample.

This level of sensitivity and specificity was almost equalled by a suggested protocol in which the frozen lymphocyte death rate was used as a highly sensitive test to triage positive samples to the more time consuming and expensive tests measuring lymphoblast respiratory function and TORC1 activity. This protocol provides a promising biomarker that could assist in more rapid and accurate diagnosis of ME/CFS.

Daniel Missailidis, **Oana Sanislav**, **Claire Y. Allan**, **Sarah J. Annesley** and **Paul R. Fisher**

Full text: https://www.mdpi.com/1422-0067/21/3/1142/htm

Cerebral Blood Flow is Reduced in ME/CFS During Head-up Tilt Testing Even in the Absence of Hypotension or Tachycardia: A Quantitative, Controlled Study Using Doppler Echography

Highlights

- Doppler imaging to measure cerebral blood flow is feasible during tilt testing.
- Cerebral blood flow in ME/CFS patients is reduced during tilt testing.
- 90% of ME/CFS patients show abnormal cerebral blood flow reduction on tilt testing.
- Cerebral blood flow reduction correlates with symptoms of orthostatic intolerance.

Abstract

Objective

The underlying hypothesis in orthostatic intolerance (OI) syndromes is that symptoms are associated with cerebral blood flow (CBF) reduction. Indirect CBF measurements (transcranial Doppler flow velocities), provide inconsistent support of this hypothesis. The aim of the study was to measure CBF during a 30 min head-up tilt test (HUT), using Doppler flow imaging of carotid and vertebral arteries, in individuals with chronic fatigue syndrome/myalgic encephalomyelitis (ME/CFS), a condition with a high prevalence of OI.

Methods

429 ME/CFS patients were studied: 247 had a normal heart rate (HR) and blood pressure (BP) response to HUT, 62 had delayed orthostatic hypotension (dOH), and 120 had postural orthostatic tachycardia syndrome (POTS). We also studied 44 healthy controls (HC). CBF measurements were made at mid-tilt and end-tilt. Before mid-tilt, we administered a verbal questionnaire to ascertain for 15 OI symptoms.

Results

End-tilt CBF reduction was 7% in HC versus 26% in the overall ME/CFS group, 24% in patients with a normal HR/BP response, 28% in those with dOH, and 29% in POTS patients (all $P < .0005$). Using a lower limit of normal of 2SD of CBF reduction in HC (13% reduction), 82% of patients with normal HR/BP response, 98% with dOH and 100% with POTS showed an abnormal CBF reduction. There was a linear correlation of summed OI symptoms with the degree of CBF reduction at mid-tilt ($P < .0005$).

Conclusions

During HUT, extracranial Doppler measurements demonstrate that CBF is reduced in ME/CFS patients with POTS, dOH, and even in those without HR/BP abnormalities.

Significance

This study shows that orthostatic intolerance symptoms are related to CBF reduction, and that the majority of ME/CFS patients (90%) show an abnormal cerebral flow reduction during orthostatic stress testing. This may have implications for the diagnosis and treatment of ME/CFS patients.

C.M.C van Kampen, **Freek W.A. Verheugt**, **Peter C. Rowe**, **Frans C. Visser**

Source: Science Direct http://bit.ly/3d3uSKN

CRISPR-ing Herpes Simplex Virus

Herpes simplex viruses establish lifelong persistent infection in sensory neurons of infected individuals, a phenomenon called latency. Latent viral genomes are "dormant" but can sporadically reactivate and begin replicating in a phase called lytic replication, which is often accompanied by shedding of virus particles and the appearance of painful lesions. There is no vaccine to prevent infection with either herpes simplex virus type 1 or 2 (HSV-1 or -2), and currently available therapeutics do not clear latent viruses or prevent their reactivation.

The emergence of CRISPR genome editing tools has inspired renewed efforts for preventing the reactivation of latent viruses by targeting and cleaving their genomes. An exemplary CRISPR editing system consists of the bacterial nuclease Cas9 and a small "guide" RNA molecule. The RNA molecule, which is complementary to the target sequence, guides the nuclease to its destination, where the nuclease cleaves the target DNA. CRISPR/Cas9 complexes can be introduced into cells by various mechanisms. For example, viruses engineered to encode the nuclease and the guide RNA can be transferred into cells using a technique called transduction.

A team at Harvard Medical School recently determined that specifically designed guide RNAs (http://bit.ly/2WoXYOC) not only inhibit lytic replication of HSV-1, but can also cleave and edit latent HSV-1 genomes, thereby inhibiting their reactivation.

The authors of the study screened 58 potential guide RNAs for their ability to direct the cleavage of HSV-1 target DNAs in vitro. In this assay, they incubated individual nuclease/guide RNA complexes together with different DNA substrates containing various target sequences and measured cleavage efficiency by gel electrophoresis.

The guide RNAs that led to the best cleavage efficiency were then further tested for their efficacy in inhibiting HSV-1 lytic replication in human fibroblast cells. The authors transduced the cells with the various nuclease/guide RNA complexes, infected them with HSV-1, and measured viral (lytic) replication by plaque assay (http://bit.ly/2IS3otK). Although several of the guide RNAs significantly reduced viral replication, the guide RNA targeting the UL30 region, which encodes the viral DNA polymerase, reduced viral levels by more than 10,000-fold.

To see whether this editing system could inhibit reactivation of latent HSV-1 genomes, the authors infected cells with a replication-defective HSV-1 strain, thus mimicking latency, and transduced the cells with Cas9 nuclease and various guide RNAs that had been effective in the in vitro cleavage screen. They then reactivated the latent virus by "superinfecting" the latently infected cells with wild type HSV-1 and measured the ability of the individual guide RNAs to inhibit this reactivation.

The replication-defective strain encodes a green fluorescent protein, allowing the authors to distinguish between replication of the wild type input HSV-1 and the reactivated virus. When used individually, four of the guide RNAs reduced reactivation of latent viruses by about 100-fold. However, the authors were able to reduce reactivation by an additional 10-fold by targeting two genes simultaneously with two different guide RNAs, suggesting that one can achieve an increased effect by combining several guide RNAs.

Sequencing analyses also showed that some of the CRISPR/Cas9 complexes introduced detrimental mutations into the target sequence, and that the guide RNA targeting the UL30 gene led to mutations in about 40-80% of the latent viral genomes. Although these mutations did not reduce the actual number of latent genomes, they did reduce their ability to reactivate.

During latency, HSV-1 and HSV-2 exist as circular chromosomes wrapped around cellular chromatin components called nucleosomes. This temporary association with nucleosomes implies that portions of the latent viral DNA are tightly folded and inaccessible to guide RNAs. Because the UL30 target site was consistently cleaved so efficiently, the authors speculate that this site may be in an open portion of the viral DNA that is more accessible to guide RNAs than other sites in the viral genome. If this is true, future guide RNA design strategies could include sequencing latent genomes using methods that identify open or accessible DNA.

Previous attempts to eliminate and/or prevent the reactivation of latent HSV virus in infected cells have had limited success. This study provides the first evidence that CRISPR/Cas9 can efficiently edit latent HSV genomes. Other studies are underway to determine whether CRISPR/Cas9 can edit the HSV genome during latent infection in the resting sensory neuron host cell and other in vivo models. Although more work is needed to figure out how to deliver Cas9 and guide RNAs to latently infected sensory or other neurons in vivo, the therapeutic potential of CRISPR/Cas9 in the context of HSV latency is encouraging, particularly when considered in combination with other existing therapies.

Gertrud U. Rey

Source: Virology Blog http://bit.ly/39UbY6Z

Hilda Bastian Appointed to Lead the Independent Advisory Cochrane Group

In October 2019, Cochrane announced its commitment (http://bit.ly/2QliNXB) to a full update the Cochrane Review Exercise therapy for chronic fatigue syndrome (http://bit.ly/3d1QyqA). The statement noted plans for: "a comprehensive review of the protocol, which will be developed in consultation with an independent advisory group that we intend to convene. This group will involve partners from patient-advocacy groups from different parts of the world who will help us to embed a patient-focused, contemporary perspective on the review question, methods and findings."

Cochrane is now pleased to announce that **Hilda Bastian** has been appointed to lead the independent advisory group.

Hilda has been a health consumer advocate and researcher, and has held many roles with healthcare bodies.

She is also author of the popular PLoS blog "Absolutely Maybe", which looks at the uncertainties in medicine, and reported on the contents and conduct of the Cochrane Review Exercise therapy for chronic fatigue syndrome.

Her knowledge and understanding of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and the methodology of systematic reviews, saw broad support for her blog posts from consumers and researchers alike.

Cochrane's Editor-in-Chief, **Dr Karla Soares-Weiser**, said: "**Hilda**'s appointment marks the first steps in Cochrane's commitment to update the Cochrane Review on exercise therapy for chronic fatigue syndrome.

We look forward to learning from the process of involving an independent advisory group of patients, clinicians and researchers in the development of Cochrane Reviews."

Read more here: http://bit.ly/2WjqykK

Media Attention for Prof. Leonard Jason's Publications

It's really amazing how much attention of the media the work of **prof. Jason** – advisor to the ME Global Chronicle since the very start of the magazine in 2014 – and his team of researchers generates.

Below is just of the last two months:

- 2020 (Feb. 21). Clinical Advisor. Most youth with chronic fatigue syndrome undiagnosed http://bit.ly/2vvvcBa
- 2020 (Feb. 20). Medical Press. Most youth with chronic fatigue syndrome undiagnosed http://bit.ly/2TRO9ap
- 2020 (Feb. 19). Drugs.Com. Most youth with chronic fatigue syndrome undiagnosed http://bit.ly/2xLtPiB
- 2020 (Feb. 19). Newsbreak. Most youth with chronic fatigue syndrome undiagnosed http://bit.ly/2x0iESJ
- 2020 (Feb. 18). **Kristin Claes Mathews**. NIH-funded study reveals many youth living with undiagnosed chronic fatigue syndrome. http://bit.ly/38Toanh
- 2020 (Feb. 13). **Darcel Rockett**. Chicago Tribune. Chronic fatigue goes undiagnosed for Latino, black children - Chicago Tribune http://bit.ly/2wYxXv2
- 2020 (Feb. 12). **Cort Johnson**. Health Rising. Childhood ME/CFS takes a hike. http://bit.ly/3bbEtxx
- 2020 (Feb. 5). **Lara DeSanto**. Health Central. How tired is too tired. Sometimes sleep eludes us all. But a new study found that some of us may be walking around with an undiagnosed chronic fatigue syndrome. http://bit.ly/2We3eEZ
- 2020 (Feb. 4). **Simon McGrath** (http://bit.ly/2UabVxj). ME/CFS Research Reviews. **Leonard Jason** research finds that many young people have ME/CFS. http://bit.ly/38Y64k2
- 2020 (Feb. 3). **Alayne Trinko** (http://bit.ly/2vuuQe2) DePaulia. DePaul researchers unmask misunderstood chronic illness. http://bit.ly/39Y6ybo
- 2020 (Jan. 30). **Valerie Nikolas**. Chicago Health. Chronic Fatigue Syndrome Is Debilitating but Often Dismissed http://bit.ly/2ISZp01
- 2020 (Jan. 30). Healio. Most kids, teens with chronic fatigue syndrome are undiagnosed http://bit.ly/39VPuCM
- 2020 (Jan. 27). **Kristen Dalli** (http://bit.ly/3b1qABW). Consumer Affairs. Chronic fatigue syndrome can go undiagnosed in many young people. http://bit.ly/38TAOCR
- 2020 (Jan. 23). Science Daily. **Many Youth** Living with Undiagnosed Chronic Fatigue Syndrome http://bit.ly/2U9or0a
- 2020 (Jan. 24). **Bernie Tafoya**. WBBM News radio. Young People with chronic fatigue go undiagnosed. Researcher http://bit.ly/3aYnZs9
- 2020(Jan. 16). Chronic Fatigue Syndrome and Mono in College Students. Press Release. http://bit.ly/2QlkAMj

New Support For ME/CFS Research From The Kavli Foundation

The aim of the research is, among other things, knowledge about disease mechanisms and biomarkers that can detect the disease, as well as contributing to an evidence-based treatment program for patients with ME/CFS. Since 2011, the Kavli Foundation has supported biomedical research into ME/CFS at the Haukeland University Hospital. The collaboration has now been extended with a financial contribution to the research group of NOK 4.7 million for 2020 and 2021.

"We believe that this is often a reversible disease", says **Øystein Fluge**, professor and consultant at the cancer department at Haukeland University Hospital. Together with **Professor Olav Mella**, he heads the research group for ME / CFS at the hospital in Bergen. "But we still lack important knowledge about the disease. We see a great need for research on both disease mechanisms and possible treatment measures", says Fluge. The research group at the Haukeland University Hospital therefore combines clinical studies with translational laboratory studies where researchers analyze samples from patients participating in the clinical studies.
Overall goals for the research group over the next two years:

- increase knowledge of disease mechanisms and possible biomarkers of ME/CFS
- clarify the role of immune cells and possible autoantibodies in the disease
- contribute to an evidence-based treatment program for patients with ME / CFS

The support from the Kavli Foundation makes it possible to carry out advanced experiments in the research laboratories. The experiments focus on, among other things, energy metabolism, gene expression in purified immune cells, and autoantibodies in patients' blood. With the help of funds from the Kavli Foundation, the research group is also working on laying the foundations for further clinical studies. This work includes a new study to develop better methods for measuring symptom change and activity levels among participants, including the use of activity clocks. "We are very grateful that the Kavli Foundation wants to support the research on ME / CFS. The research is in an exciting phase, and we believe that the next few years will bring increasing insight into the causes and development of the disease", says **Olav Mella**. "It is with great pleasure that the Kavli Foundation continues to support the research group at Haukeland University Hospital for two new years. Sustained underfunding means that our contribution to the researchers' tireless work is still needed to provide knowledge that can help more people", says CEO of the Kavli Foundation, **Inger Elise Iversen**.

Source: Haukeland University Hospital / Kavlifondet
http://bit.ly/2QlKShn

News From the OMF

Dear friends:

We realize that you take your philanthropy seriously, and we are honored by your belief in our mission and our efforts to end ME/CFS. The accomplishments contained in the following, OMF 2019 Year in Review, are only possible because of you; your investment in our work and your dedication to our shared vision of a world free from ME/CFS. We are grateful beyond words...

OMF 2019 Year in Review -Organizational Accomplishments

We Welcomed:

- New SAB members: **Alain Moreau**, PhD and **Michael Snyder**, PhD
- New Chief Medical Officer: **Ronald Tompkins**, MD, ScD
- New VP of Philanthropy: **Kathleen Morgen**
- New Ambassadors: **Karin Alvtegen** and **Jaqueline Ko**

We also:

- Launched a new ME/CFS Collaborative Research Center at Uppsala University in Sweden
- Sponsored two productive scientific symposia at Stanford and Harvard
- Sponsored two Community symposia
- Provided free live streaming at Stanford Community symposium
- Funded high-level research on multiple projects
- Established OMF Canada
- Assembled Harvard-affiliated Clinicians to explore new collaborationsamong specialists

ME/CFS Collaborative Research Center Updates

Your 2019 contribution funded open and collaborative research across the globe, conducted with impeccable standards and integrity, by researchers and clinicians of the highest caliber.

Stanford University Collaborative Research Center

Directed by **Ronald W. Davis**, PhD, Professor of Biochemistry and Genetics

Open Medicine Foundation has been the lead funding partner of **Dr. Davis**'s ME/CFS research team at Stanford University since 2014.

2019 Research Focus:

- Nanoneedle technology development
- Technology to detect Red Blood Cell Deformability
- Tryptophan Metabolic Trap
- Trace heavy metal detection
- Development of a new test to expand the number of pathogens detectable in cell free DNA/RNA
- Direct DNA sequencing of genes possibly connected to ME/CFS

2019 Publications Include:

- Published a research paper on the Nanoneedle (http://bit.ly/3a7huTO)
- Published a research paper on the Metabolic Trap Hypothesis (http://bit.ly/2WdV5QS)
- Published a research paper on Red Blood Cell Deformability (http://bit.ly/2TUem8p)

Please visit our website (http://bit.ly/39XZDyL) for more information about projects at the Stanford CRC

2019 End of Year Message from **Ronald W. Davis**, PhD, and **Janet L. Dafoe**, PhD (http://bit.ly/33xZPm9)

Harvard Affiliated HospitalsCollaborative Research Center
Co-Directed by **Ronald G. Tompkins**, MD, ScD
Sumner **M. Redstone Professor** of Surgery,
Harvard Medical School Founding Director

Co-Directed by **Wenzhong Xiao**, PhD
Assistant professor of Bioinformatics and Director of the Inflammation & Metabolism Computational Center at Massachusetts General Hospital

In 2018, OMF launched a funding partnership with Harvard affiliated hospitals, including Massachusetts General Hospital (MGH), Brigham and Women's Hospital (BWH), and Beth Israel Deaconess Medical Center (BIDMC).

This research collaboration seeks to conduct clinical and basic science studies to characterize the dynamic biological changes that occur during a change in symptom expression of ME/CFS patients

Projects launched in 2019 include:

- BWH iCPET biorepository plasma proteomic and metabolomic studies
- PASS/CAT diagnostic tool development
- Symposiums Science and Community

Please visit our website (http://bit.ly/39TBtW4) for more information about projects at the Harvard CRC

Uppsala University, SwedenCollaborative Research Center
Directed by **Jonas Bergquist**, MD, PhD
Full Chair Professor in Analytical Chemistry and Neurochemistry

In 2019, OMF funded and launched the ME/CFS Collaborative Research Center at Uppsala University under the direction of **Jonas Bergquist**, MD, PhD.

This new Collaborative Center focuses on the targeted molecular diagnosis of ME/CFS with the goal of evidence-based strategies for interventions.

Current projects include:

- Kynurenine studies in ME/CFS
- Autoimmunity aspects of ME/CFS
- Endocrine hormone disturbances in ME/CFS

Please visit our website (http://bit.ly/2TWVhCC) for more information about projects at the Uppsala CRC

We look forward to 2020 with Hope for All

Australian Report

Australian Report:
The National Centre for Neuroimmunology and Emerging Diseases (NCNED), Menzies Health Institute of Queensland, Griffith University, Australia. By **Professor Sonya Marshall-Gradisnik**, **Ms Cassandra Balinas**, **Ms Natalie Eaton -Fitch**, **Dr Helene Cabanas**, **Dr Leighton Barnden**, **Professor Don Staines** and the **NCNED Team**, Menzies Health Institute Queensland, Griffith University, Australia.

NCNED continues to report evidence of impaired Transient receptor potential (TRP) ion channels and calcium signalling in ME/CFS. This world leading research highlights numerous TRPs are involved in the pathology of ME/CFS. NCNED continues to expand the scope of TRP and calcium investigations in ME/CFS.

We report on two key papers:

- "Health-related quality of life in patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: An Australian cross-sectional study".Quality Life Research:**Natalie Eaton-Fitch**, **Samantha Johnston**, **PawelZalewski**, **Don Staines** and **Sonya Marshall-Gradisnik**. This research represents the largest study to assess quality of life in Australians diagnosed with ME/CFS. NCNED report for the first time the significant impact this illness has on quality of life. Our researchers analysed 480 survey responses submitted by ME/CFS patients. **Eaton-Fitch** reports significantly low quality of life scores due to cognitive symptoms, sleep and sensory disturbances, and autonomic and immune dysfunction. This publication provides evidence of the disabling effects of ME/CFS and the impaired quality of life which hopes to motivate the Australian public health community to renew public health policies and increase focus on patient care.
- "Transient receptor potential melastatin 2 (TRPM2) channels are overexpressed inmyalgic encephalomyelitis/chronic fatigue syndrome patients" Journal of Translational Medicine: **Cassandra Balinas**, **Helene Cabanas**, **Don Staines** and **Sonya Marshall-Gradisnik**

These world first findings show that TRPM2 is significantly increased in expression in NK cells in ME/CFS patients compared with healthy participants. The NCNED team also found the additional protein, CD38, that acts together with TRPM2 to cause NK cell induced lysis, was not changed in expression in ME/CFS patients compared to healthy participants.

Hence TRPM2 expression in NK cells from ME/CFS patients appears increased to potentially compensate for less calcium entering NK cells to perform cell lysis.

These recent and very promising results from NCNED provide new insights in the pathomechanism of ME/CFS. NCNED is continuing its investigations to develop strategies for identification of TRP and calcium signalling in ME/CFS as well as potential treatment interventions to improve the life of individuals with this illness.

Submitted by
Prof. Sonya Marshall-Gradisnik

The Prevalence of Pediatric ME/CFS Community-Based Sample

Leonard A. Jason, **Ben Z. Katz**, **Madison Sunnquist**, **Chelsea Torres**, **Joseph Cotler** & **Shaun Bhatia**

Abstract

Background

Most pediatric prevalence studies of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) have been based upon data from tertiary care centers, a process known for systematic biases such as excluding youth of lower socioeconomic status and those less likely to have access to health care. In addition, most pediatric ME/CFS epidemiologic studies have not included a thorough medical and psychiatric examination. The purpose of this study was to determine the prevalence of pediatric ME/CFS from an ethnically and sociodemographically diverse community-based random sample.

Method

A sample of 10,119 youth aged 5–17 from 5622 households in the Chicagoland area were screened. Following evaluations, a team of physicians made final diagnoses. Youth were given a diagnosis of ME/CFS if they met criteria for three selected case definitions. A probabilistic, multi-stage formula was used for final prevalence calculations.

Results

The prevalence of pediatric ME/CFS was 0.75%, with a higher percentage being African American and Latinx than Caucasian. Of the youth diagnosed with ME/CFS, less than 5% had been previously diagnosed with the illness.

Conclusions

Many youth with the illness have not been previously diagnosed with ME/CFS. These findings point to the need for better ways to identify and diagnose youth with this illness.

Source: **Springer**, 23 January 2020
https://link.springer.com/article/10.1007%2Fs10566-019-09543-3

Dr. Nancy Klimas, director of neuroimmune medicine at Nova South Eastern University, Miami has decades of clinical experience with M.E. patients. In this audiotape he sheds light on what can be done by patients re. the COVID 19-outbreak

Of course pwME run a greater risk when exposed. They have enough immune cells but they've been working so hard that they depleted their resources. What you can do, you can read here:

1. Reading the guidelines which come out:
   - handwashing
   - avoiding people who may be infected, standing 6 feet away from other people. You've been doing this for many years, so you're good at it.
   - clean the surfaces you're touching at home and in your car like doorknobs etc.
   - about wearing a mask: it's more important people who are coughing and sneezing wear a mask.

About the life cycle of the virus: it goes through your nose into your airways, attaching itself to the cells in the nose and the bronchial tubes. So everything done to rinse the spots where viruses tend to attach to the cells works like hand washing, and for your nose like with salt spray. Particularly when you've been outside.

Use nose sprays that contain e.g. xylitol (USA) and cellulose sprays (Europe and Canada) that can block viruses from binding. Asthmatics should take their meds to prevent inflammation in the bronchial tube.

2. Improving the immune system

There are two things wrong with your antiviral cells:

- with ME they have exhausted the nutrients they use to kill viruses.
- their energy pathways have been impaired through the creation of oxidative stress, the cell reacting by shutting down its energy production.
  - Improve your oxidative stress with nutrients: ideally by eating healthy but most of the patients don't have the energy to stand in the kitchen and chop and eat. So use supplements like co-Q10 (ubiquinol, 200 mg for a month or two and then drop down to 100 or 50), NAC cysteine, a precursor of glutathione, the nr 1 antioxidant in the body, penetrating all tissues including the brain (600 mgs 1-2x a day; not at bedtime, as it keeps you awake), vitamin C and carnitine.
  - Do this first before driving the cells to work harder as then they will crash. After that add the supplements which improve cell-function – B12 (methyl B12 or hydroxyl B12), (methyl)folate.

- Immunovir (available in Europe and Canada) (isoprene, an aminoacid) improves the energy in the cell and its cytotoxic function. It's not available in the USA- isoprene can be bought over the counter though. Caution: it can go down the pathway to uric acid and gas and can cause gout or renal stones. So drink a lot and take two days off per week. It's an antiviral against HHVs. Corona is a different virus, but the way these drugs work is to enhance your antiviral immune system and to reduce your suspectibility and reduce your outcome should you become infected.

And don't panic. There's no one better at social isolation than an ME patient.

Dr.Klimas is expecting this to pass in June or July. Corona viruses have a seasonal rate of exposure that peaks in March and April and then fade down in some two months.

Source: https://youtu.be/pkGXiJ1jM14
Summary of transcript: ME Centraal
https://mecentraal.wordpress.com/2020/03/17/covid-19-m-e

9. Severe ME

25% ME Group and Severe ME Day 2020

For Severe ME Day -8 August 2020, and as part of their 25 year anniversary celebrations, 25% ME Group have launched their Stories and Images Project to give people with Severe ME a voice, to make them visible.

Members of both the 25% ME Group charity and of the 25% ME Facebook group have been invited to participate in a project to raise awareness of life with Severe ME and the work of the 25% ME Group. They have been asked to write between one line to 25 lines about aspects of their life with severe ME and/or to submit a photo/image which portrays some detail of their life

Their stories/photos will be added to the 25% ME Group website and some of the stories/photos will be featured in the Summer 2020 newsletter (or maybe also in an earlier newsletter) and in awareness and fundraising projects including Severe ME Day in August.

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

Who are 25% ME Group? What is Severe ME Day?

Severe ME Day is a special day for 25% ME Group charity and for people with Severe ME. 25% ME Group is the only charity concerned specifically with the needs of those severely affected by ME. Being formed 25 years ago, celebrating their 25 year anniversary this year, they have an unrivalled wealth of experience and as such they are generally seen as an authority on Severe ME.

They are active in campaigning for better diagnosis, treatment and care of people with Severe ME, for example being a stakeholder in the NICE review, supporting use of the ICC, undertaking surveys about various aspects of Severe ME, disseminating information, etc, and we are a respected voice for people who are the most affected by ME

Severe ME Day is a day to remember everyone who is suffering or who has ever suffered from Severe and Very Severe Myalgic Encephalomyelitis.

Severe ME Understanding & Remembrance Day: This day aims to bring public attention to the illness for the sake of all those presently suffering from Severe Myalgic Encephalomyelitis and to remember all those who have died from ME. https://25megroup.org/severe-me-day-2020

A day to honour the strength of spirit of all those who have endured and continue to endure decades of suffering and profound physical dysfunction and yet receive little, or no recognition or help, but rather continue to experience gross misrepresentation and misinterpretation of their illness and profound disability.

What is the significance of 8 August?

Sophia Mirza

This was the birthdate of **Sophia Mirza**. **Sophia** was bed-bound with very severe Myalgic Encephalomyelitis and was a victim of widespread ignorance and medical abuse. Her doctors couldn't understand why she wasn't getting any better (indicating they had no basic understanding of Myalgic Encephalomyelitis, nor had they kept up-to-date with medical knowledge).

Consequently, they did not believe that Myalgic Encephalomyelitis was a physical disease and **Sophia** was forcibly taken from her bed/home by social workers, police officers and doctors, and taken to a psychiatric facility where she received inappropriate treatment and care. **Sophia** subsequently died as a result at the age of 32. Her postmortem revealed that she did, in fact, have Severe Myalgic Encephalomyelitis. Unfortunately, this same inexcusable abuse still goes on. You can read **Sophia**'s story here http://www.sophiaandme.org.uk/

Spread the word

Please help us to spread the word about 25% ME Group to reach those who have Severe ME so that they can join us and submit their stories and images.

Link to updates about Severe ME Awareness Day https://25megroup.org/severe-me-day

You can find out more about the 25% ME Group on their website. Or you can join the charity. They have membership (UK and overseas memberships) for those who suffer from Severe ME and their carers. There is also associate membership for those who don't have Severe ME but want to learn more about the condition and want to show their support https://25megroup.org/join

You can join the 25% Severe ME Group News Page on Facebook.

There is a hidden, private Facebook group for those who have Severe ME: a safe place for members to share information, to give and receive advice from others who are severely affected. This group does not show up on Facebook searches. Those who have severe ME can make initial contact via the 25% Severe ME Group News Page.

To contact me regarding the 25% group or submission of stories I can be contacted at: johnsonjan@hotmail.co.uk

Jan Johnson

Special Issue of Healthcare on "ME/CFS – The Severely and Very Severely Affected"

A special issue of Healthcare (http://bit.ly/2TUAyzd) (ISSN 2227-9032). This special issue belongs to the section "Chronic Care (http://bit.ly/2Uh5poJ)".

Deadline for manuscript submissions: 31 December 2020

Special Issue Editors
Dr. Kenneth Friedman Guest Editor
Laboratory Corporation of America Holdings, Burlington, United States
Interests: Chronic Fatigue Syndrome

Dr. Lucinda Bateman Guest Editor
Bateman Horne Center, Salt Lake City, United States
Interests: Clinical collaboration with all scientists engaged in discovering biomarkers and improving both diagnosis and treatment of ME/CFS

Prof. Kenny Leo De Meirleir Guest Editor
Professor emeritus Physiology, Pathophysiology and Medicine, Vrije Universiteit Brussel

Interests: the severely ill ME/CFS patients; newly discovered infections in ME/CFS ; chronic zoonotic infections ; immune abnormalities in ME/CFS and their consequences ; the microbiome and intestinal inflammation in ME/CFS and chronic zoonotic infections.

Special Issue Information

Dear Colleagues,
"ME/CFS—The Severely and Very Severely Affected" is a proposed themed Special Issue of Healthcare concerning housebound and bedbound Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) patients.

Our intent is to redefine ME/CFS as the serious disease that it is. Up to this point in time, all literature and case definitions of ME/CFS have excluded severely and very severely affected patients, and diagnosis, patient management, and case definitions have been based on the ambulatory ME/CFS patient. Although never formally studied, it is estimated that twenty-five percent of ME/CFS patients are either severely or very severely affected. What other disease's diagnosis, patient care, and case definition exclude the most severely ill twenty-five percent?

We aim to document, describe, and promulgate what can and should be done for this hidden patient population. By focusing on the severely affected, it is our hope that the pathophysiological nature of the disease will be better accepted and understood, and effective methods of symptom reduction and patient improvement will be placed in the medical literature. ***Kenneth J. Friedman****, Ph.D. is serving as Guest Editor of the issue, with* ***Drs. Lucinda Bateman*** *and* ***Kenny DeMeirlier*** *serving as co-guest editors. If you would like to consider submitting a manuscript or have questions concerning the submission of a manuscript, please contact the guest editors.*

Dr. Kenneth Friedman
Dr. Lucinda Bateman
Prof. Kenny Leo De Meirleir
Guest Editors

Manuscript Submission Information

Manuscripts should be submitted online at http://www.mdpi.com by registering (http://bit.ly/2x0Jf1S)and logging in to this website (http://bit.ly/39WKRZf). Once you are registered, click here to go to the submission form (http://bit.ly/3d7QN3y). Manuscripts can be submitted until the deadline. All papers will be peer-reviewed. Accepted papers will be published continuously in the journal (as soon as accepted) and will be listed together on the special issue website. Research articles, review articles as well as short communications are invited. For planned papers, a title and short abstract (about 100 words) can be sent to the Editorial Office for announcement on this website.

Submitted manuscripts should not have been published previously, nor be under consideration for publication elsewhere (except conference proceedings papers). All manuscripts are thoroughly refereed through a single-blind peer-review process. A guide for authors and other relevant information for submission of manuscripts is available on the Instructions for Authors (http://bit.ly/3aUKHBE) page. Healthcare (http://bit.ly/2vtmSBV) is an international peer-reviewed open access quarterly journal published by MDPI.

Please visit the Instructions for Authors (http://bit.ly/3aUKHBE) page before submitting a manuscript. The Article Processing Charge (APC) (http://bit.ly/3b3zyOO) for publication in this open access (http://bit.ly/38Vo0Mm) journal is 1000 CHF (Swiss Francs). Submitted papers should be well formatted and use good English. Authors may use MDPI's English editing service (http://bit.ly/2IQcdnO) prior to publication or during author revisions.

This special issue is now open for submission.

Myalgic Encephalomyelitis Emergency Room Information

Information compiled from patient input and expert documents to assist patients and caregivers in communicating with medical professionals. Detailed medical information can be found in the Myalgic Encephalomyelitis: International Consensus Primer for Medical Practitioners (2012).

Myalgic Encephalomyelitis (ME) is one of the most complex illnesses wherein multiple body systems are affected and presents with difficult illness-specific biochemistry. ME may be mistakenly diagnosed as Chronic Fatigue Syndrome, Fibromyalgia, and/or POTS. Reactions to suggestions vary. Patient's input must be valued to prevent harm.

A cursory online illness overview is unlikely to provide medical expertise sufficient to diagnose or treat someone with ME. ME patients arriving at an ER may be result of downstream effect caused by any of the following underlying multi-system pathophysiology abnormalities. See more information on page 4-6 of the ME IC Primer.

- Neurological abnormalities
- Abnormal sleep patterns
- Cerebral spinal fluid abnormalities
- Central nervous system signal altered
- Immune impairments – decreased NK cell function & Th1 shift towards Th2
- Energy production and ion transport impairments
- Cardiovascular and autonomic impairments
- Endocrine system dysfunction
- Gastrointestinal tract impairments
- Impaired oxygen exchange

Treatment suggestions can be found on page 16 of the ME IC Primer - https://bit.ly/2IX1SHD

Key to proper emergency care, is understanding cardinal symptom Post Exertional Neuroimmune Exhaustion (PENE). Sometimes labeled Post Exertion Malaise-PEM. PENE is the exacerbation of all illness symptoms after activity exceeding the energy production window. The cascade of symptoms after even minor activities can lead to symptoms so severe patients seek emergency help. This "crash" is often seen 24-48 hours after activity. The ER visit is likely to induce PENE. Minimizing PENE by treating patients with care can help reduce the likelihood of a return to the ER in the next 48 hours.

Inappropriate Treatment in Any Medical Setting Can Exacerbate This Debilitating Disease

PRIORITY for any medical provider to be part of the solution and not part of the problem, is a good understanding of things that will exacerbate the illness. Tips to avoid exacerbating the symptoms of an ME patient: (See IC Primer page 13)

- Activity (including mental) exacerbates all symptoms. Minimize interaction as much as possible.
- Elevated heart rate with orthostatic intolerance – inability to stand for length of time. Standing/sitting are outside energy production envelope of most patients. Many patients MUST recline to reduce PENE. Reclining exacerbates symptoms in some patients. Seek patient/caregiver input to avoid exacerbating illness. (pg 3)
- Immune system dysfunction causes susceptibility to bacteria and viruses. Isolate patients. (pg 8)
- Low blood volume, dehydration and electrolyte imbalance are common - IV saline helpful to stabilize patients (pg 18)
- Patients cannot regulate body temperature – patients may need warming blankets (pg 3)
- Oxygen levels may look fine, but studies show exchange of oxygen at cellular level is impaired. Patients have high oxidative stress. Listening to the patient is vital to avoid exacerbating the situation. Not all ME patients respond well to oxygen. Oxygen may be helpful or harmful. Listening to the patient's response to oxygen is important. (pg 3)
- Cognition issues lead to Impaired concentration, slowed thought, difficulty with word finding and memory lapses. Clearly written notes with detailed instructions is vital to avoid future ER visits. (pg 7)
- Overload phenomena - Sensitivity to light, noise, vibration, odor, taste, touch and motion can cause temporary period of immobilizing physical and/or cognitive exhaustion leading to inability to communicate and possible seizures. Patients usually require darkened and quiet room – avoid exposure to odors including colognes. (pg 18)
- Patients must avoid unnecessary activity – patients have impaired depth perception, muscle weakness and poor coordination. Provide wheelchair if requested to minimize risk of falls and avoid PENE. (pg 7)
- Serious side effects from medications are common. including increased risk of dangerous withdrawal symptoms when trying to stop a medication. Prescribing lowest dose possible is recommended (pg 6) NOTE: ME patients may experience extreme levels of pain. None of these warnings should limit access to adequate pain treatments.
- Homeostasis is impaired - many systems are easily affected so care must be taken to avoid shocking the system. Start all medications as low as possible and increase very slowly.
- Paralysis of muscles is seen in ME. Resting muscles is vital to recover function. Patients know their safe limits. Listen to patients – provide assistance to bathroom – do NOT pressure to move around more than necessary. (pg 7)
- Anesthesia warning - use following with caution (sparingly) catecholamines, sympathomimetics, vasodilators and hypotensive agents. Avoid histamine releasing anesthetic and muscle relaxing agents if possible. (pg 20)
- Surgery – Pre and post-surgery considerations covered on page 20 of ME IC Primer

Patients CANNOT exercise safely. Patients have been harmed by recommendations to gradually increase activity or exercise. Pushing patients to be more active is not recommended. Exercise is contraindicated due to the damaged oxygen exchange and impaired energy production which leads to exacerbation of symptoms. Patients can use muscles for short bursts but the oxygen exchange malfunction leaves muscles starved for oxygen leading to a cascade of symptoms including chest pains and shortness of breath. See Workwell Foundation information: https://bit.ly/2RHw5gm

Examples of Issues That Lead to ER Visit

Pain - Headaches and severe widespread pain can be a downstream effect of several core features of ME. ME pain can reach extreme levels and may require strong medications to sufficiently alleviate pain. Research has shown brain inflammation and central nervous damage may be involved. Suicide from unrelieved pain and ongoing suffering from multisystem issues is a significant cause of death in this patient population. (pgs 3, 4 & 5)

Gastro-intestinal tract is affected causing nausea, abdominal pain, bloating and irritable bowel syndrome. Chronic enterovirus of the stomach, intestinal dysbiosis and hypermeable gut should be considered. (pg 6)

Genitourinary issues such as urinary urgency or frequency and excessive urination at night are common. Bladder infections may occur without normal signs such as fever. (pg 18)

Ocular system is affected leading to inability to focus, blurred vision, night blindness and temporary blindness. (pg 7)

Symptoms for medical issues may not present normally - Many patients will not have a fever during infections. Other signs and symptoms normally associated with bacterial or viral infections or other health issues may not be present. Gallbladder issues is one area that may cause illness or GI issues, but does not present with normal symptoms.

Understanding ME Experience

ME patients suffer a living death that is life changing and, in most cases, lifelong. These patients need to avoid many activities a normal person would undertake, including social interaction. Progression of ME is not well understood but a significant percentage may become so ill as to require a caregiver and a subgroup may require 24/7 care and tube-fed.

Importance of Rest

"Those patients who are given a period of enforced rest from the onset have the best prognosis... Those who, on the false assumption of 'neurosis', have been exhorted to 'snap out of it' and 'take plenty of exercise' the condition finally results in a state of constant exhaustion... Any excessive physical or mental stress is likely to precipitate a relapse." Dr. Ramsay stated about ME in 1986

ME has one of the lowest health-related quality of life scores of any disease. "The condition can be as disabling as multiple sclerosis, rheumatoid arthritis, systemic lupus erythematosus and congestive heart failure." The Health-Related Quality of Life for Patients with ME/CFS (2015)

For detailed information see the International Consensus Criteria for Myalgic Encephalomyelitis and the International Consensus Primer for ME. Links can be found at www.MEadvocacy.org/resources

As with all support group files, this is prepared only for informational purposes and is not to be considered medical advice.

10. ME And Children

Health-Related Quality of Life in Adolescents With CFS/ME

A cross-sectional population based Norwegian study by **Wenche Ann Similä**, **Vidar Halsteinli**, **Ingrid B. Helland**, **Christer Suvatne**, **Hanna Elmi** & **Torstein Baade Rø**

Abstract

Purpose

The primary aim was to measure health related quality of life (HRQoL) in a Norwegian cohort of adolescents with Chronic Fatigue Syndrome (CFS/ME). A secondary aim was to identify factors initial to diagnosis, at time of diagnosis and at follow-up that were associated with HRQoL.

Methods

In this cross-sectional population-based study, HRQoL was measured by PedsQL Generic Core scale (PedsQL4.0) in 63 adolescents with CFS/ME. In addition, fatigue was measured by PedsQL Multidimentional Fatigue scale (PedsQL-MFS), depressive symptoms were measured by the Short Mood and Feelings Questionnaire (SMFQ), and disruption in school activities was measured by The De Paul Pediatric Health Questionnaire (DPHQ-N). Data were also collected from patient journals and patient interviews.

Results

Age at diagnosis was 15 (2) years (mean (SD)), and four out of five participants were female. Time from diagnosis to reply was 39 (22) months. Adolescents with CFS/ME reported PedsQL4.0 score 50 (17), and boys reported a better score than girls (64 vs 47, CI (-27;-6)). There were positive associations between overall HRQoL and follow-up by school teacher, school attendance or participation in leisure activities.

There were negative associations between overall HRQoL and delayed school progression, having been to rehabilitation stay and depressive symptoms.

Conclusion

HRQoL in adolescents diagnosed with CFS/ME was low compared to healthy adolescents. The associations between HRQoL, healthcare provided, teacher follow-up, school attendance and participation in leisure activity may provide information of value when developing refined strategies for follow-up of adolescents with CFS/ME.

Possible causal relationships must however be explored in future longitudinal studies.

Source: http://bit.ly/2TW5AGZ

11. News from

Australia

Submissions to the Federal Disability Royal Commission

Emerge Australia will be making an organizational submission to the Federal Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

We have created two short surveys to help us to develop a submission that is representative of people's experiences of living with ME/CFS, and that of their carers, across Australia.

The surveys will be available until 31 March 2020. If you live with ME/CFS or care for someone with ME/CFS, and have the energy to do so, we would greatly appreciate you taking the time to participate. The first survey (http://bit.ly/33n0syG) is interested in experiences of people living with ME/CFS (and can also be completed by carers on their behalf) and the second (http://bit.ly/2U8lwVs) is for carers to reflect on their own experience. The Disability Royal Commission is also encouraging people to make their own individual submissions. There is more information about the Royal Commission and submission process below.

What is the Disability Royal Commission?

Emerge Australia is preparing an organizational submission for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. The Disability Royal Commission was established by the Australian Government in 2019 and will run for three years to 2022.

The inquiry will provide recommendations to government on how to:

- prevent and better protect people with disability from all forms of violence and abuse, neglect and exploitation
- achieve best practice reporting and investigation processes
- promote a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation

The Royal Commission is accepting submissions from individuals and organizations on any of these topics. Submissions can relate to experiences with government, institutions and support services, and community.

Emerge Australia's submission to the Royal Commission

A submission to the Royal Commission is an opportunity to highlight negative encounters that some people living with ME/CFS in Australia have had when interacting with government institutions, medical and other support services, and community. The Royal Commission is also an avenue to advocate for increased understanding of and improved treatment of the condition. Emerge Australia will therefore be making an organizational submission on behalf of people in Australia living with ME/CFS.

Emerge Australia has identified the categories of 'violence and abuse' and 'neglect' as most related to the experiences of people living with ME/CFS, and will therefore be focusing on these two areas in the submission. For people living with ME/CFS, experiences of 'violence and abuse' may include undergoing forced treatments, and 'neglect' may include an inability to access appropriate services and supports. The Royal Commission's definition of terms are detailed below.

Emerge Australia acknowledges that carers of people living with ME/CFS can also experience 'violence and abuse' and 'neglect' when carrying out this role. This can include exclusion from attending medical appointments to support the person you provide care for or inability to access your own support services such as mental health services or Carer allowance.

How you can assist us to develop our submission

Emerge Australia is conducting two short surveys to assist us in representing the experiences of people living with ME/CFS, and their carers, across Australia.

The first survey is interested in the experience of people living with ME/CFS. Carers are also welcome to take this survey on behalf of people that they care for. A second survey has been developed specifically to capture the experiences of carers who have experienced violence, abuse or neglect themselves. We estimate that each survey will take 10-20 minutes to complete, but it could take considerably longer depending on how much detail you provide and on your level of disability.

Emerge Australia is greatly appreciative of anyone who takes part in this survey, however please be aware that participating could be distressing as you will be asked to recall experiences of violence, abuse and neglect. Please do not feel obligated to participate and be aware that if you begin the survey you are able to stop at any time.

If you wish to take part, the survey for experiences of people living with ME/CFS is here (http://bit.ly/33n0syG) and the survey for carer experiences is here.(http://bit.ly/2U8lwVs) Please participate in the survey/s most relevant to you.

Emerge Australia will also be drawing on information from other sources, such as findings from the 2019 Health and Wellbeing survey, to develop our submission.

Individual submissions

The Royal Commission also welcomes individual submissions. While Emerge Australia does not have the capacity to provide one-on-one support for individual submissions, we will be producing a simple how-to guide to assist you to do this on your own. Disability advocacy organisations around Australia have also been funded by the Royal Commission to support people who wish to submit an individual submission. You can find your closest advocacy service at the Disability Advocacy Finder (http://bit.ly/2IRI5s5) or contact the Royal Commission on 1800 517 199.

Support for participation

Emerge Australia unfortunately is not able to offer counselling support to people who participate in our survey or who are impacted by the Disability Royal Commission process. The Department of Social Services has launched a national, free counselling and referral service for people affected by the Disability Royal Commission. This service operates through the Blue Knot Foundation 9am-6pm AEST weekdays and 9am-5pm AEST weekends on 1800 421 468 or 02 6146 1468. Blue Knot also provide webchat and text message options which is accessible via their website (http://bit.ly/2IOXbyz).

Definition of terms

The Royal Commission defines 'violence and abuse' as including assault, sexual assault, constraints, restrictive practices (physical and chemical), forced treatments, forced interventions, humiliation and harassment, financial and economic abuse and significant violations of privacy and dignity on a systemic or individual basis.

The Royal Commission defines 'neglect' as including physical and emotional neglect, passive neglect and willful deprivation. Neglect can be a single significant incident or a systemic issue that involves depriving a person with disability of the basic necessities of life such as food, drink, shelter, access, mobility, clothing, education, medical care and treatment.

The Royal Commission defines 'exploitation' as the improper use of another person or the improper use of or withholding of another person's assets, labour, employment or resources including taking physical, sexual, financial or economic advantage. Please note that Emerge Australia does not intend to focus on 'exploitation' in our group submission. Further information about the Royal Commission is here (http://bit.ly/39Vxjx5).

Source: **Emerge Australia**
http://bit.ly/2vtmqnc

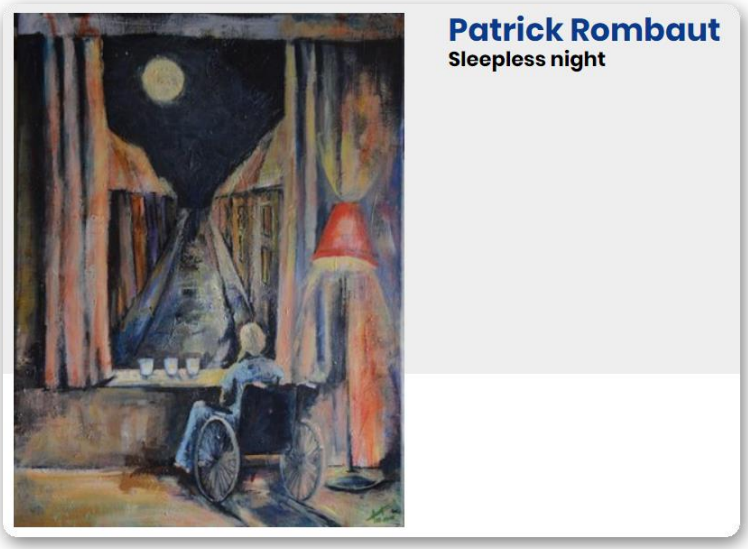
Belgium

In Belgium, the Superior Health Council has been working on a new medical guideline for chronic fatigue syndrome (they still prefer to call it CFS without using the term ME). Patient organizations have been invited to provide feedback but it remains unclear if their concerns will be taken on board.

Meanwhile, several events are being prepared for the International ME/CFS day on 12 May. Besides the annual Millions Missing events, there will be an art exposition called "ME in woord en beeld" on 9 May in Gent.

Creative work such as poetry, photographs, and paintings of patients and their loved ones will be presented to the general public. Using art as a medium, the organizers hope to increase awareness of the illness and offer insight into the experiences of people living with ME/CFS. There will also be a premiere of a short compilation video in which patients from all over Belgium explain how ME/CFS has affected their lives.

Patients and their loves ones who would like to present their artwork on 9 May in Gent, Belgium can contact organizer **Dascha van Beurden** (info@12me.be) of the patient organization 12ME. The artwork has to have some connection to ME/CFS and it should be possible to send it online through email. Because of the high transport costs, the organizers won't be able to include original paintings or artwork that cannot be downloaded online.



For those interested, a catalogue of last years edition is available at: http://bit.ly/2I2cpzP

Michiel Tack

(See also https://www.facebook.com/MEBelgium for other events)

Canada

Update from ICanCME Research Network: Let's stop ME together

Since its inception in September 2019, thanks to a catalyst network grant funded by the CIHR Institute of Musculoskeletal Health and Arthritis (IMHA), the Interdisciplinary Canadian Collaborative Myalgic Encephalomyelitis (ICanCME) Research Network has stretched its wings. Myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), is a complex chronic multi-systemic disease whose etiology remains poorly understood. ME is life-altering and in its more severe forms can be life-threatening. An estimated 600,000 Canadians currently have ME.

Among the first ICanCME Research Network goals is the launch of our website by the end of March, 2020. Equally important, we are organizing several Town Hall meetings across Canada. We will be reaching out to Canadians living with ME, as well as researchers and clinicians to collaborate to address this 21st century medical enigma.

The ICanCME Research Network is an excellent example of patient engagement given their key role in network governance. In March, we will also launch our ME Stars of Tomorrow competition to support new talent in the field of ME/CFS by offering bursaries for graduate students and postgraduate fellowships across Canada. In April, we plan to launch the New Frontiers ME Discovery Grants competition to sustain the formation of interdisciplinary research teams. Both competitions are part of our strategy to attract researchers and clinicians from other fields as well as to develop the next-generation of scientists interested in ME. We look forward to hearing from you, and hope to count of all of you as new members soon!

Prof. Alain Moreau PhD
Director, Interdisciplinary Canadian Collaborative Myalgic Encephalomyelitis Research Network

Source: http://bit.ly/3aI6PPs

ME|FM Society of BC and CCDP receive $20,000 grant from Vancouver Foundation

We are pleased to announce that the ME|FM Society of BC (http://bit.ly/3cTnFgk), in partnership with the Complex Chronic Diseases Program (CCDP) (http://bit.ly/339TlcV) at BC Women's Hospital + Health Centre, a program of the Provincial Health Services Authority, has received a Vancouver Foundation (http://bit.ly/3aN7Fuj) Convene grant of $20,000 to support a community engagement project that will begin to examine the unmet needs of British Columbians living with Myalgic Encephalomyelitis (ME).

The project

This project will allow community, research, clinical, and health decision-maker stakeholders to inform a framework for a provincial ME needs assessment. While focused on ME patients in BC, this inquiry – as the first of its kind in a Canadian context - will create unique knowledge to inform strategies, policies, and pathways for improved care for ME patients.

What is a Vancouver Foundation Convene grant?

Convene grants from the Vancouver Foundation support project teams to gather information, meet with key stakeholders to learn more about the complex issue, and to articulate the research question, methodology, and partnership. The intended output of a Convene grant is a viable plan for a larger research project that can then be submitted to funders for consideration.

Our Society's project partnership with CCDP

The ME|FM Society of BC and the CCDP look forward to working together on this first phase of important research work in the province. Stay tuned for project updates and specific invitations to participate. Congratulations to the application team.

Millions Missing Global Campaign

May 9th - 17th, 2020

Can you believe this is our FIFTH year?
Millions Missing Canada will again be joining the Millions Missing global campaign for health equity led by #MEAction (http://bit.ly/2vel2Vg)in the US.

As we do every year, we'll be customizing our campaign to suit our own uniquely Canadian style with content relevant to ME within the Canadian landscape and context. Just as in previous years too, we want to help make sure your event is a success, so there will be lots of tools offered and support available.

People with ME and their supporters from around the world will be rallying for increased government funding for research, clinical trials, medical education, support and public awareness.

There's more than a week to hold your visibility actions this year and planning has already begun for many Canadians. Events are already in the works for Vancouver, Calgary, Montreal and Halifax. There's lots of terrific plans bouncing around and the ideas are endless — educate the public, hold a rally, pass out literature, plan to meet with your elected officials or hold a fundraiser. These are just some of the many great ways you can increase awareness of ME and help to make a difference.

Low-key activities include hosting an Unrest screening in your home, participating online or simply sending us your bio or a photo of your shoes so we can make sure you're represented at events across our country.

Meantime, if you'd like to connect with people in your own area to see what's up or discuss plans with other like-minded advocates, join one of the 'Connect' advocacy groups in your area. Be sure to register your event as soon as possible with us — even if it's not yet fully planned — so we can promote it widely on our social media platforms.

Lots more details are coming soon. Stay tuned!

Advocacy Groups for Discussion and Planning:
Connect British Columbia - http://bit.ly/37yzxAB
Connect Alberta - http://bit.ly/2UUQF0u
Connect Ontario - http://bit.ly/2SrjQqk
Connect Québec - http://bit.ly/2HrSavo
Connect Canada - http://bit.ly/37o1x9O

MillionsMissingCanada@gmail.com

Submitted by **Barbara Fifield**

Czechia

The development of ME/CFS guidelines in the Czech Republic was rejected. Patients do not want to accept it.

The negotiations between the patients' organization Club of patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (Club ME/CFS), the Ministry of Health and Medical Associations were held throughout the year 2019 (see ME Global Chronicle #34, Dec 2019).

The participants agreed on the need to create ME/CFS diagnostic and treatment guidelines for general practitioners, which have been missing for a long time here, and to give a proposal to include ME/CFS into the Disabling Conditions Registry.

These intentions were also supported by the Minister of Health Mgr. and **Mgr. Adam Vojtěch**, MHA, so the negotiations were proceeding promisingly. However, the Guarantee Committee, an authority responsible for Czech national methodology of clinical guidelines developments, makes the final decision in this matter.

The meetings and minutes of the Committee are not public. Therefore, all the Czech patients and their families were awaiting tensely and with a great hope the outcome of the decisive meeting held in December 2019. Unfortunately, at the end of January 2020, we were informed that the Commission had refused the development of the guidelines for ME/CFS in Czech Republic. It was a big disappointment for all of us. Although the Club ME/CFS has done utmost to succeed the Committee did not hear our voices.

Despite of the unfavorable development of the situation we do not want to give up our long-standing efforts to make progress. The sick people with ME/CFS are in desperate health and social status here and until we have the official guidelines, no improvement can be expected. What are we going to do?

At first, a virtual postcard campaign has emerged immediately in response to the negative decision of the Guarantee Committee. Sick people from the Czech and Slovak Republics send their own photos and experience about lives with the non-recognized severe illness.

It is their message to the entire society including medical institutions and doctors which have still denied the existence of ME/CFS.

Most importantly, we need to know the exact reasons of the rejection in order to public it and to be able to oppose the Committee decision. We are convinced that we have a legal right to do so because it is a decision about lives a lot of people. Accordingly, we have officially requested the Guarantee Committee to provide us the text of its decision made on December 2019.

Currently we are preparing further steps to reverse the negative decision about the creating ME/CFS guidelines in the Czech Republic. We believe that our state cannot ignore us indefinitely.

Author: Redaction of ME/CFS.cz
Contact for patients' organization
Club of patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome:
me-cfs@seznam.cz
http://me-cfs.eu
https://www.facebook.com/MEcfs.cz

Denmark

The Danish ME Association has sent and posted the following open letter to "Danish health politicians," with a very impressive list of international signatories. It seemed important to give this letter wide circulation.

Open Letter to Danish Health Politicians

On March 14th 2019, a unified Danish Parliament voted to acknowledge WHO's diagnostic classification of Myalgic Encephalomyelitis (ME – G93.3) as a biological illness and to separate ME from Functional Disorders.

The proposal passed is aligned with the current international scientific knowledge about ME.

Based on analysis of more than 9.000 peer-reviewed studies, the Institute of Medicine, Centers for Disease Control (CDC), National Institutes of Health (NIH), as well as the advisory report from the Dutch Health Council, conclude that ME is a serious chronic multisystem, biological disease that substantially limits the activities and quality of life of patients.

ME is a complex and physical disease for which there is currently no cure. It is not a psychological or psychosomatic disease. There is strong scientific evidence of neurological/autonomic dysfunction, immunologic and inflammatory pathologies, microbiome perturbation, metabolic/mitochondrial as well as cardiac abnormalities (and more) in patients.

Based on this scientific evidence, there is an imminent need to change the narrative of ME to avoid that patients are misdiagnosed or further stigmatized by falsely equating the disease with (chronic or unexplained) fatigue, deconditioning or psychosomatic classifications, like functional disorders, medically unexplained symptoms, somatoform disorders, somatic symptom disorder, functional somatic syndrome, neurasthenia, or bodily distress disorder/syndrome.

Patients have for decades been prescribed treatments like Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET), based on the idea that they suffer from "false illness beliefs", fear of exercise or that they are deconditioned. This 'deconditioning hypothesis' as well as the 'psychosomatic hypothesis' of ME is not supported by biomedical research.

The treatments based on these hypotheses (CBT/GET) have produced no robust evidence in the past two decades, as the US Agency for Healthcare Research and Quality systematic literature review, and reanalysis of the largest ever study on CBT/GET (PACE trial) have shown.

The CDC has recently removed its recommendations for CBT and GET from its website.

Furthermore, and of dire importance, patients internationally for more than 20 years have continually reported deterioration from following the advice of their doctors to gradually increase their exertion levels based on a GET protocol.

Post-exertional malaise (PEM), a worsening of symptoms after minimal physical or mental exertion, is the hallmark characteristic of the disease. GET worsens PEM and has the potential to cause lasting harm for patients with ME.

There is international consensus that funding biomedical ME research is the only way to create better insights into the physiological mechanisms of this debilitating disease, so we can provide better and more efficient care, based on the needs of patients and the biomedical nature of the disease, as well as effective treatments and potentially a cure. Biomarkers are also needed for accurate diagnosis.

More funding for biomedical research into ME is therefore urgently needed.

We ask that the Danish Government will strongly consider a long-term investment in biomedical ME research. It is an absolute priority and the only way to make the necessary progress to help stop what the CDC calls a “hidden health crisis”.

We would be happy to provide you with further insights based on our expertise, if needed.

This letter has also been sent to the Minister of Higher Education and Science, as well as the Danish Health Authority.

Source: Virology Blog,
Trial by Error http://bit.ly/39Ufqi9

England

ME Research UK is pleased to announce an open call for applications from researchers wishing to investigate the causes, consequences and treatment of ME/CFS. We will continue to offer research grants for projects related to the biology or treatment of ME/CFS, and we are now also able to fund PhD studentships to help encourage new researchers to embrace a career in the field.

We are happy to consider projects in all areas related to the biology or treatment of ME/CFS, but our main areas of interest currently include the following:

- Muscle fatigue – underlying mechanisms and potential therapies
- Brain and nervous system – structural and functional changes
- Immune system – autoimmunity and the role of specific antibodies
- Metabolomics and the search for diagnostic biomarkers
- Symptomatic impact of ME/CFS on other organ systems

For more information about our research grants and PhD studentships, please visit our website.

Research grants: meres.uk/grants http://bit.ly/2xEWAND
PhD studentships: meres.uk/phds http://bit.ly/3d1IR3z

Submitted by **Dr. David Newton**

Finland

ME patients are disappearing ... They are disappearing into their homes and beds and are in need of help. Because they can't get along with other people, and even visits are often too much - their voices are not heard and their suffering becomes invisible.

Who are these missing ones, and what was their life like before the illness and what is it like now?

In December 2018, the ME/CFS channel released the video "Invisible - Stories of a severe ME/CFS disease", which tells the story of several Finnish "missing" ME patients https://youtu.be/qxukxGKDqiU (English subtitles)

Help Finnish ME patients become visible and have their voices heard!

For example, you can help:

- By participating in the Millions Missing event on International ME Awareness Day, either by giving your support by coming to the site or by signing up for a volunteer by writing to us at millionsmissing.finland@gmail.com
- By sponsoring The #MEAction Network, whose international campaign is Millions Missing, you can find donation guidelines on their website
- By sponsoring the Finnish Medical ME / CFS Association, donation guidelines can be found on their website http://bit.ly/2TUi3uP
- By supporting ME's biomedical research and accelerating the discovery of ME's biomarker, treatment and curative care by donating to, for example, the Open Medicine Foundation for Exploratory Research, please visit their website.
- Supporting close ME patients, assisting with everyday activities such as shopping, cooking, cheering them up with small gestures, simply asking "how are you".

Ours is not a rare disease

Finland uses the European definition of rare diseases, which states that a disease is rare if it occurs in at least one person in 2000. This means about 3000 patients in relation to the Finnish population.

In Finland, it is estimated that there would be 10 to 50 thousand ME patients, well above the definition of a rare disease.

It is reasonable to assume that a worldwide estimate of 80% -90% of undiagnosed ME patients is also true in Finland.

Jukka Lumio, Specialist in Infectious Diseases at A-studio 28.1.2019:

"Half of the Finnish doctors have heard nothing about this disease [ME/CFS] in primary education - and this is no 'hit theme' either".

This broadcast of A-studio can still be watched at Yle Arena:
https://areena.yle.fi/1-4584913

"Fight for the treatment of chronic fatigue syndrome."

Tuulia Tiihonen, a chronic fatigue syndrome guest, and **Jukka Lumio**, a specialist in infectious diseases. What are some other ways to avoid hard crashes? In the studio, researcher **Timo Miettinen**. Hosted by **Heikki Ali-Hokka**.

Source: Millions Missing Finland
https://www.facebook.com/millionsmissingfinland

France

#MillionsMissing (http://bit.ly/2U86MFX) Campain 2020 is being organized in:

- Bordeaux (day and location to be defined)
- Paris (day and location to be defined)
- Périgueux, May 13, 2020, complete program on the following day (after the 12th)

We are still looking for volunteers for the #MillionsMissing 2020 campaign, to make sufferers of ME visible to the general public, from 9 to 17 May.

For the organization of events upstream and/or presence on D-Day (12th May), we need good will.

- Dordogne (Périgueux), May 13: information stand with installation of empty shoes, exhibition, documentary, play performed by a professional troupe.

- Ile de France (Paris)
- Aquitaine (Bordeaux)
- Normandy (Orne)

Waiting for confirmation

- Brittany (Ille et Vilaine)
- Rhône Alpes (Lyon region)

Please contact us by private message on this page
https://www.facebook.com/MillionsMissingFrance or by email:
info@millionsmissing.fr

Decision National Assembly about the AAH
Good news !!! The amount of the AAH (Allocation aux adultes handicaps) should no longer be determined based on the spouse's income. Explanations at 1'30 of this video (in French)
https://www.facebook.com/yhijnk/videos/187103069183903

The law has been modified by the National Assembly. This adoption at first reading is symbolic: despite the prior rejection motion supported by LREM members, the law was passed (including by elected officials who regularly support LREM). It is now in the hands of the Senate.

With the announcement that AAH will remain outside the RUA, this is a step in the right direction. Hoping that this will not remain an advertisement and that the means will follow. Associations must be vigilant, again and again ...

Millions Missing France thanked **Ms. Marie-Georges Buffet** for her commitment to this amendment which, if implemented, will change the lives of many people with disabilities.

Source: Millions Missing France
https://www.facebook.com/MillionsMissingFrance

Germany

First parliamentary technical discussion on ME/CFS in the Bundestag (German Parliament)

On March 5, the first parliamentary technical discussion on ME/CFS took place in the Bundestag: "ME/CFS care in Germany - utilizing potential, improving care". **Martina Stamm-Fibich**, patient representative of the SPD parliamentary group in the Bundestag and member of the health committee, organized the technical discussion together with the German Society for ME/CFS and Millions Missing Germany to improve the disastrous care situation for those affected. Representatives from many important areas took part, including MPs of the SPD parliamentary group in the Bundestag, Bündnis 90/ ie Grünen Bundestag faction and CDU/CSU Bundestag faction, representatives of the Federal Ministry of Health, the umbrella association of health insurance companies (GKV) and the German pension insurance as well as scientists and Representatives of the four German patient organizations: German Society for ME/CFS, MillionsMissing Germany, Lost Voices Foundation and Fatigatio eV

Martina Stamm-Fibich greeted those present and gave an introduction. Afterwards, **Prof. Uta Behrends** from the TU Munich/Munich Clinic, **Prof. Carmen Scheibenbogen** from the Charité - Universitätsmedizin Berlin and **Sebastian Musch**, Chairman of the German Society for ME/CFS, clarified the severity of the disease, the catastrophic supply situation and the urgent need for action on. There was a lot of interest, the participants took notes and asked questions.

After the short lectures there was an open discussion with lively participation. Over 40 people were present. This number is quite high for a technical discussion - in advance, the originally reserved room had to be replaced by a larger room due to the number of commitments. All participants received information folders from the German Society for ME/CFS and #MillionsMissing Germany, which clarify the existing problems - underpinned by data and facts - and show the most important fields of action. The Kudoboard with the messages from 150 people affected, which #MillionsMissing Germany recently handed over to **Maria Klein-Schmeink**, was laid out in the room.

It is an important step that all major parties recognize the problem and that health insurance companies and pension insurance providers are also involved. This is now being built on - with more and more advocates: inside politics. One of our next goals is to promptly set up a commission with experts and equal patient participation. **Ms. Stamm-Fibich**, #MillionsMissing Germany and the German Society for ME / CFS have sent a joint press release, which you can find here (in German): http://bit.ly/3cRba4S… A film team was also present at the technical discussion.

Source: Deutsche Gesellschaft für ME/CFS (http://bit.ly/38MpKqW) - http://bit.ly/38NEJ3P

Ireland

Dr Weir's 4 May Irish M.E. talks in Cork/Dublin/Galway/Limerick

The Irish ME/CFS Association is pleased to announce that it has arranged for **Dr William Weir**, a leading international ME expert from the UK, to give 4 ME/Chronic Fatigue Syndrome talks in Ireland this May. The talks entitled "ME: Past, Present and Future" will include questions-and-answers sessions.

Towards the end, we have included a biography of **Dr Weir**.

The talks will take place in the following venues:

- Cork Monday May 11 2020 - 7:30 PM The Kingsley Hotel, Victoria Cross, Cork, T12 P680. https://www.thekingsley.ie/location Lots of free car parking Location: see here: https://www.thekingsley.ie/location This talk is being hosted by **Yvonne Brewer** and **Michelle Dinn**.
- Limerick Wednesday May 13 2020 - 11:30 AM Great National South Court Hotel, Raheen Roundabout, Limerick V94 E77X. https://www.southcourthotel.com Free Car Parking (400 spaces) Location: see here https://www.southcourthotel.com/finding-our-limerick-hotel.html This talk is being hosted by **Sarah Warde**, co-ordinator of the Limerick ME Self-Help Group.
- Galway Thursday May 21 - 7:30 PM The Connacht Hotel, Old Dublin Road, Galway H91 K5DD (between the Bon Secour private Hospital (Renmore) and the Eye Cinema - nearer the hospital than the Cinema). https://www.theconnacht.ie Free parking (both over and underground). This talk is being hosted by **Orla Ní Chomhraí**, secretary of the Irish ME/CFS Association and coordinator of the Galway ME/CFS Support Group.
- Dublin Saturday May 16 2020 - 2 PM Radisson Blu Hotel Dublin Airport, Corballis, Dublin http://bit.ly/2w2PnXs Car parking: Reduced delegate car parking at a cost of €5.00 per day (you may need to get your ticket validated at reception) Location: see here http://bit.ly/3bWzS37 24-hour courtesy bus to & from the airport (useful as there are a lot of transport links to the airport) This talk is being hosted by **Vera Kindlon**, the Association's chairperson.

Admission: €5, on the door, to help towards the costs of organising these 4 meetings and **Dr. Weir**'s trip. We don't take pre-bookings but expect the rooms will be big enough to hold the numbers we expect to attend.

If you would like further information and/or be kept up-to-date with future events, please contact us at info@irishmecfs.org or 086-2353497.

Short biography: **Dr Weir** is a consultant physician, currently in private practice at 10 Harley Street, London W1G 9PF. Until December 2000 he was a NHS Consultant Physician at the Royal Free Hospital, London NW3, having held this position since September 1987.

His main specialty was infectious and tropical disease. He was also an examiner for the Royal College of Physicians for the Diploma of Tropical Medicine and Hygiene during the years 1987 to 2000. During this time he established a major interest in ME/CFS, because of its frequent relationship with a prior infectious disease.

His interest in this condition included the running of a clinic at the Royal Free dedicated to the care and management of patients as well as providing the basis for a number of studies which subsequently appeared in the peer-reviewed medical literature.

He was a member of the Chief Medical Officer's (of England and Wales) Working Group whose report on ME/CFS was published in January 2002. He has continued his clinical and academic interest in ME/CFS and a substantial proportion of his present practice comprises patients with this condition.

He obtained the degrees of MB ChB at Dundee University in 1972 followed by Membership of the Royal College of Physicians (UK) by examination in 1975.

He was subsequently elected a Fellow of the Royal College of Physicians of London in 1993 and of Edinburgh in 1998. He is currently an appointed member of the newly constituted UK National Institute for Clinical Excellence (NICE) Guideline Development Group for ME/CFS. The remit of this group is the replacement of the previous guidelines, published in 2007.

Submitted by **Tom Kindlon**

Italy

We had an article on CFSME published here in a very popular weekly magazine recently. I was interviewed as patient and as the President of the CFS/ME Italian Association, along with prof. **Tirelli** and **Ms. Roberta Ardino**, President of another association.
You can find it here online: http://bit.ly/2TSfYzg.

Mike Harley, who is running marathons around Europe to raise awareness and money for Invest in ME, was supposed to run in Rome at the end of the month. The marathon was unfortunately cancelled because of Corona virus, but he posted on his site just last night 4 interviews to Italian patients, both in English and Italian.

Giada Da Ros

The interviews from **Mike Harley** mentioned by **Giada** we split into three parts, of which the first one is to be found in this issue of the ME Global Chronicle with the title Italy and ME, part 1

Chronic Fatigue Syndrome: A Treatment Guide translated into Italian
Chronic Fatigue Syndrome: A Treatment Guide, 2nd Edition has now been translated into Italian. It is currently available on Amazon https://amzn.to/33bCAOk and Google Play http://bit.ly/2vZ6eu3, and will soon be available on many other platforms as well. The cost is $3.99. It has been published as an ebook, but you can easily read it on your computer. "*Questo riferimento unico nel suo genere, ora completamente rivisitato e aggiornato, comprende oltre 100 trattamenti efficaci, dagli antivirali alle vitamine, oltre a sedi di specialisti e cliniche, informazioni per l'ordine via Internet e contatti di organizzazioni CFS/ME nazionali, locali e internazionali. Le sezioni nuove ed estese comprendono protocolli medici e ricerche sulle cause e i meccanismi della malattia, tutti scritti in un linguaggio conciso e di facile comprensione. Ogni aspetto della malattia viene accuratamente esaminato, dalla diagnosi a una discussione approfondita dei sintomi, dalle terapie tradizionali a quelle alternative fino alle strategie di coping essenziali. La nuova edizione contiene capitoli per coloro che affrontano molteplici sensibilità chimiche e restrizioni dietetiche, oltre a una sezione ampliata su bambini e adolescenti con CFS/ME. Sindrome da stanchezza cronica: una guida al trattamento, seconda edizione, rimane la guida di riferimento più completa su questa malattia.*"

Erica Verrillo

Portugal

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

This is part 2, part 1 having been published in the MEGC of December 2019.

Do you know of any support groups or associations in Portugal for those suffering from ME/CFS? If so what are their aims?

Elle - No, there are none to my knowledge.

André - Only one that I'm aware of, MYOS. However, while it does include CFS patients, it's basically aimed at people suffering from Fibromyalgia.

Ana - There is no exclusive group or association for ME/CFS. We have a national association for fibromyalgia and chronic fatigue syndrome, but it has very few associates with ME/CFS, so it is ill equipped to recognize and respond to our needs. To make matters worse, some people with fibromyalgia are self diagnosing themselves with CFS because they have chronic fatigue, which is wrong and devalues the actual diagnosis.

This is a hard situation all around to solve because since people don't feel represented, they don't join the existing association, maintaining the status quo. People with ME/CFS also depend heavily on allies, thanks to how heavily the illness affects us. Most often we are not able to contribute directly to awareness or activism, as most associations are used to.

But it's hard to rally allies when the illness isn't being talked about at all in the first place, or worse, being confused with chronic fatigue. However, the worst challenge of all is that people aren't being diagnosed, so we simply don't have the numbers to make a difference. I can count with the fingers of one hand the people with the disease I've found here in Portugal. Before anything else can improve, this has to change.

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

Elle - When I first moved here, I had very low expectations. I had read that the situation here was not good, and couldn't find any associations. ME/CFS is not a diagnosis given in Portugal and is routinely conflated with fibromyalgia. However, the doctors I have seen know vaguely what it is, and acknowledge their lack of awareness.

They do not dispute that it is disabling. I found female doctors were likely to listen, be curious and work with me.

I found a less open attitude in male doctors, especially older ones, and I had a few choice comments from them. My strategies for finding doctors is to skew female, look for who is involved with EU level research orgs for their specialty, and to find doctors who publish research, often at University affiliated hospitals. In Portugal, both Coimbre and Porto have University hospitals that I have found doctors at. Also, pick a doctor who is senior enough to have some pull in ordering unusual exams.

Like in most countries, if you can be self directed, and bring literature or articles showing some proof of efficacy, the doctors will work with you to try medications or treatments. In this way, I have worked with a neurologist to try mestinon, despite her saying that ME was not considered to fall under her speciality in Portugal.

I worked with a rheumatologist to check hormones, and try hydrocortisone. She referred me to a center for hyperbaric medicine to try that. And I went to a hematologist to check for autoimmunity, MCAS and other mast cell diseases.

André - I do not think so. The doctors that diagnosed me are acquainted with CFS through Fibromyalgia. It's usually me doing research and pointing them new theories and medicines but, since many things are too recent, they're ignored.

Ana - There might be, especially doctors who deal with fibromyalgia, but I don't believe they're aware of it or interested in changing their focus to ME/CFS. I don't believe there are any who might be interested in ME/CFS as a lone entity.

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

Elle - As far as I know the government doesn't recognize it at all as a disease. The doctors know that you are ill, but they do not know the disease well. Despite these issues, I've made progress here by being self directed, and because generally the Portuguese people want to be helpful.

Because the country has an abundance of hospitals and clinics, it's not difficult to get appointments. Private insurance is inexpensive, and public healthcare is free. There have of course been setbacks and difficulties.

You must learn here that arguing and debating is cultural, but someone who says "no, no, no, it cannot be!" for an hour might suddenly say "yes but of course, you are right!" at the end. And there is a lot of bureaucracy and paperwork involved in coming here. But, I've made more progress here than in the two other countries I've been sick in!

André - It's not legally acknowledged and many doctors don't believe it, dismissing it as depression. Fibromyalgia (and I mention it because of what I said earlier about MYOS) as gained some exposure and has been recognised as a condition a couple of years ago - but CFS is largely ignored by the media, the medical community and government officials.

Ana - They don't. And that's the biggest challenge we face. I doubt I would have ever received a diagnosis through the National Health Service, in which most people rely, especially if they are ill enough to not be able to hold a job. Beyond that, there are no official guidelines.

The positive part of this is that we don't end up involuntarily admitted to psych wards or forced into GET. The negative is that we receive no care whatsoever, because there is none to be had. Doesn't stop the mistreatment, however. I've had one doctor tell me, after diagnosis, that ME/CFS doesn't exist, probably because he never heard of it.

Mike Harley

Scotland

Note: deadline to participate is 24th March!

Myalgic Encephalomyelitis (ME) Survey

The Scottish Health Council is looking for people who are living with a diagnosis of ME to give their views about what support they would like to see in place in Scotland.

These views will be used to help the Scottish Government address gaps in knowledge and understanding about the care and support needs of those who are affected.

If you would like to be involved you can complete an online survey at: https://t.co/GXaUhQthPg?amp=1

The closing date is 24th March 2020.

If you would like to contribute but would prefer to take part in a telephone interview or face-to-face discussion, please contact an engagement office in your area. Find your nearest office at: http://bit.ly/33kfEfO

Source : **MP Carol Monaghan**
http://bit.ly/2WglDko

South Africa

12 May around the corner

12 May is around the corner.
For those who don't know it is International ME/CFS awareness day.
Florence Nightingale was born on 12 May and it is believed she might have had ME. We are planning to do something for 12 May this year. It might not be as big as previous years, but we will participate in the #MillionsMissing initiative.

Love.
Retha Viviers
Source: Millions Missing Africa https://www.facebook.com/MillionsMissingAfrica

Message from **Retha**

A few months ago founder and director of the ME/CFS Foundation of South Africa was diagnosed with cancer. On March 11, 2020 she sent a short update:
Dearest Friends

I had my 2nd chemo session yesterday! I will have to ask for the room with a bed next time as I talk way too much and don't get to rest. Even yesterday one patient told me I look too well to have the other illness (ME) You probably saw that 2 of my cancer counts went down significantly. It means the cancer is still growing but at a much slower speed, after session 1!

Without everyone's love, emotional and physical and financial support things would have been very different. Even sharing a post is making a difference.

Love to all, ***Retha***

Retha would still have been on a waiting list to get chemo on the public health system if you did not contribute to our fundraisers to assist her to have private health care. Each one of you contributing to her fundraiser is helping to save her life. Please, she needs more money to continue with chemotherapy.

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

To contribute to Retha's medical treatment and care, see this page:
https://gogetfunding.com/imhopeful-retha

Source: The ME/CFS Foundation of South Africa http://bit.ly/2Wd1NXn

Sweden

Health care uses knowledge gaps as an excuse for passivity at ME/CFS

When myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is noticed in the media, the lack of knowledge about the disease mechanisms and disagreement in the medical profession is often emphasized. Caregivers use the knowledge gaps as an excuse for inaction. It is therefore important to point out that there is much that the researchers actually agree on and that the care of this disadvantaged patient group must be improved. ME/CFS was first observed as a pathological residual condition after certain infections.

The cardinal symptom is "post-exertional malaise" (PEM), a strong fatigue and general symptom exacerbation after physical or mental exertion, often with some delay. Other key symptoms are fatigue that cannot be rested, sleep difficulties and neurocognitive problems (for example, concentration difficulties, poor working memory and slow processing of information). Most patients also exhibit a complex mixture of autonomic, immunological and endocrine symptoms as well as pain. The disease has been recognized by the World Health Organization (WHO) since 1969.

ME/CFS is not a social infection and no cultural disease. The disease has been found everywhere it has been sought: in all social groups, in all ethnic minorities and in all geographical regions. Studies show that a patient with ME/CFS is often severely impaired, which is also acknowledged by researchers and clinics working with the patient group.

The disease has a strong tendency to become chronic, although the prognosis for young people seems to be better. In 70–80 percent of cases, the triggering factor is an infection, but the disease can also occur in other ways and is sometimes gradual. It is well documented that some pathogens are specific risk factors for developing ME/CFS, for example Epstein-Barr virus. Physiological aberrations have been demonstrated in a large number of studies, but there are shared opinions about the significance of the findings and there is no clear understanding of the pathophysiology.

Some examples of findings that are of interest and could provide important clues are functional, chemical, and structural abnormalities in radiological studies of the brain, impaired cytotoxicity of NK cells, signs of autonomic, and mitochondrial dysfunction and an unknown, soluble factor in patients' blood serum that affected several different measurements. Physiological and cognitive anomalies have been demonstrated after exertion, which supports PEM as an objective phenomenon.

The controversy surrounding ME/CFS has primarily concerned a treatment model that is based on the fact that the disease is sustained by negative perceptions and reduced fitness. The model has been tested in a number of treatment studies that have shown moderate results in subjective efficacy measures. The results have been rejected by many researchers, as no objective improvement has been demonstrated and the effect is not greater than one would expect from systematic bias. An examination shows that the underlying model lacks scientific support.

There have also been shared opinions about the diagnostic criteria. British psychiatrists tried to redefine ME/CFS as idiopathic chronic fatigue, which has been rejected by other researchers. There has been uncertainty about exactly how the patient group should be defined, and several different diagnostic criteria have been proposed. However, this uncertainty does not mean that ME/CFS does not exist.

It is not acceptable to refer patients with ME/CFS to a primary care provider who doubts the existence of the disease. Patients need help with diagnosis, symptom relief and supportive measures. A new SBU report concludes that this is best done at specialist care, which so far only exists in a few places. The regions must take greater responsibility for this patient group and meet the need for specialized care.

ME/CFS exists and will not disappear.

Sten Helmfrid, associate professor of physics, member of the Swedish National Association for ME patients (RME) and **Sture Eriksson**, associate professor, Umeå University, medical doctor, specialist in general internal medicine and geriatrics; Vice Chairman, The Swedish National Association for ME Patients (RME) in Läkartidningen, February 17, 2020 http://bit.ly/3aLrd2f

Läkartidningen is a Swedish medical journal (http://bit.ly/38CSceY) which was first published in 1965 by the Sveriges Läkarförbund (Swedish Medical Association) (http://bit.ly/2W7nsQw), an organisation founded in 1904.

The Netherlands

Light up ME on May 12

Over the last few years, the efforts of two people in particular resulted in a growing number of buildings, bridges, stations etc being lit up in blue light in the Netherlands on the night of May 12, World ME Day. Because of one of the two people suddenly not wanting to participate anymore this year, this important event cannot follow through, and it will have to be set up again. If anyone is willing to pick up this task, please send an email to info@let-me.be and we will pass it on to the only remaining organizer.

ICC-primers sent to General Practitioners

The Dutch ME/CFS Association started a fundraiser in December with the aim to send the Dutch translation of the doctor's manual (Internal Consensus Primer, ICP 2012) of the International Consensus Criteria (ICC, 2011) to as many GPs as possible. Every patient could sign up their own GP for this, before February 2.

On February 11 the ME/CFS Association published a follow-up article with the title 'ICP given to your GP, what now?' which holds useful tips on how to deal with the distribution of the ICP to one's own GP, once received by them http://bit.ly/2wa9K4V.

The ICP has been translated by Group ME-The Hague (Groep ME-Den Haag), the petitioner of the Dutch civilian's initiative which still has great impact https://www.facebook.com/GroepMEDenHaag (See elsewhere in this edition of the ME Global Chronicle) and the ME/CFS Association (ME/cvs Vereniging), and has partially been financed by Support Group ME and Disability (Steungroep ME en Arbeidsongeschiktheid).

On 2nd March as many as 750 ICPs had been forwarded to the same number of GPs.

ME Central: more information in English

ME information channel ME Central https://www.facebook.com/MECentraal, which was founded in August 2016, has created a subsection for articles written in English https://mecentraal.wordpress.com/english. This has recently been put online and contains updates from the European Petition (see Petitions in this edition of the ME Global Chronicle) and from the DX Revision Watch, from British WHO/SNOMED 'guard dog' **Suzy Chapman** (see WHO and SNOMED CT news in this edition).

The aim is to publish more and more landmark articles in this subsection. So make sure to take a look now and then.

12. Petitions

European Petition to Recognize and Subsidize Myalgic Encephalomyelitis as a Biomedical Disease

Signed Over 13.000 Times! Let's get on and Reach 20K…

"It is possible to add signatures as long as the petition is open. There is no time limit on how long a petition can be open. We don't know yet when it will be closed.

So you can still help by signing the petition online or collecting signatures on paper! Please send signatures on paper before April, so we can forward them to the Committee on Petitions in time.

We are trying to collect as many signatures as possible before the meeting of the Committee on Petitions (March 17) and plenary meeting (April 1/2 or 22/23). After these meetings the Committee on Petitions will decide how to proceed."

The Petition can be Signed by Everybody All Over The World via Sheets! Regardless of age and country.

- Online the petition can be signed only by European citizens.

We need to show the EU that there is massive support for the resolution!

- Signing on line (only European citizens).If you are an EU citizen you can still support the petition if you haven't done so already! Please click here (http://bit.ly/2QnsG7j) for instructions.

- Signing on paper (everybody, of every age, from everywhere!)

If you (also) want to support the petition by signing or collecting signatures on paper, please find a template here (http://bit.ly/2vruzIE) that you can print or fill out digitally. You can also download and print the cover picture of this article which shows the template to be used as well.

- transferring the forms by mail… You can photograph or scan the printed paper sheet and send it to: eu.me.petition@gmail.com Please make sure the scans or photos are sharp and well-lit.

- or by snailmail!

No scanner? No problem except for an envelope and a stamp. Send your sheets by post to:

Evelien van den Brink

p/o Molenkamp 54 4171 BP Herwijnen, Netherlands	p/o Sint-Laurentiusstraat 87 9700 Oudenaarde, Belgium

The next – important – steps ahead

The petitioner, **Evelien van den Brink** let us know the following schedule, which due to the COVID 19-outbreak has been postponed, not yet known till when.

"On March 17 the Committee on Petitions intended to vote on the motion for a resolution on ME. Our team has seen the final draft and it looks very good.

If the Committee adopts the motion, the next step is a vote in plenary, in which all MEPs participate. This was to take place on April 1/2 or April 22/23, most likely in Brussels.

The European Parliament had to take measurements due to Coronavirus, but all Committee meetings will take place as usual, as things are. Yet this may change by the day of course.

On March 27 MEP Pascal Arimont was to meet Director General of Researcher and Innovation **Eric Paquet**. **Alice** will attend the meeting on behalf of our group and **Nancy** will represent European ME Alliance – EMEA. We have prepared the meeting in detail and hope that it will lead to concrete progress."

Just now she informed us that this entire schedule has been postponed without definite dates due to the covid19-outbreak. As soon as more is known, we will inform you likewise. Please follow on the fb-page http://bit.ly/2IQx4XZ

Open letter, signed by ME-experts

"*We are also working on an open letter that will be signed by as many international ME scientists as possible. There are already quite a lot of big names on the list! We hope the number of signatories will increase further and this will become a great success. It will hopefully help to increase the pressure on the decision makers in the EU.*

In the meantime the number of signatures for the petition has exploded! Online there are now 2599 signatures. On paper we now have 10,679 signatures. This totals to: 13,278!

It's an avalanche! So many people have given their best."

A word of gratitude

"On behalf of the group I would like to extend our warmest thanks to everyone who has made this unbelievable achievement a reality. And I want to give a shout out to our friends from Germany and Austria. The response from these countries in particular is absolutely amazing. Sehr vielen Dank!"

Petition still open, at least till the beginning of April

"*It is possible to add signatures as long as the petition is open. There is no time limit on how long a petition can be open. We don't know yet when it will be closed. We are trying to collect as many signatures as possible before the meeting of the Committee on Petitions (March 17) and plenary meeting (April 1/2 or 22/23). After these meetings the Committee on Petitions will decide how to proceed.*

So you can still help by signing the petition online or collecting signatures on paper! Please send signatures on paper before April, so we can forward them to the Committee on Petitions in time.

When we hear what the Committee decides, we will definitely share the news to inform everyone about what will happen next!"

Evelien van den Brink

Also read the one but last update here (http://bit.ly/3b3LCjf)

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

Sign this petition: http://bit.ly/2xjbjuF
Almost 7500 fellow sufferers already preceded you. And it is of utmost importance for a better (research) future for all pwME!

This is what is being demanded:

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

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

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

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

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

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

Why?

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

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

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

So, once more the link to sign:
http://bit.ly/2xjbjuF

13. Events


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

2020 CMRC Conference Videos Now Available

On Tuesday 10 and Wednesday 11 March the UK CFS and M.E. Research Collaborative (CMRC) held its annual conference in Bristol. Despite several international speakers being unable to travel due to Covid-19, the conference was well attended and participants heard some of the latest ground-breaking research and collaborations from across the world.

Speakers at the conference included **Prof Chris Ponting**, who spoke on the Biomedical Partnership application for funding and his work on whether T cell clonality being a M.E./CFS biomarker, and also **Dr Michael VanElzakker** who joined via web-link from Massachusetts. **Dr VanElzakker** spoke on some of the history of M.E. and his work on abnormal cerebrovascular reactivity among people with the condition. You can see a full list of speakers on the conference programme (http://bit.ly/33mT3zv) which is still available on our website.

We have uploaded the videos of the presentations onto our Youtube Channel (http://bit.ly/3d8ajN6) and will be taking steps to live-stream the next conference to enable people at home to watch and participate in the discussions. We will also be producing a conference report which will be available on our website.

Action for ME
http://bit.ly/2vov5Hk

[CANCELLED] Invest in ME's Next Colloquium and Conference

Our next research Colloquium and public Conference will be in 2020.
The Thinking the Future Young/ECR conference will be on 27th May 2020.
The BRMEC10 research Colloquium will be on 28th May - 29th May 2020.
The IIMEC15 Conference will be on 30th May 2020.

BRMEC10

The Invest in ME Research Biomedical Research into ME Colloquium 10 (#BRMEC10) will take place in London over two days from 28th - 29th May 2020. The BRMEC* Colloquium is the largest biomedical research into ME colloquium in the world and #BRMEC10 will have representation from almost thirty of the major institutes and organisations from over fifteen countries, including participation from USA's Centers for Disease Control (CDC) and National Institutes of Health (NIH).

The tenth Colloquium aims to increase international collaboration in research into ME and is a closed researchers' meeting with presentations from leading researchers and a major networking opportunity.

The Invest in ME Research Colloquiums have spawned a number of positive initiatives over the years and are the most successful research meetings for forming new research initiatives for ME with multiple collaborative initiatives being formed across continents.

The BRMEC10 research Colloquium in London will precede the IIMEC15 annual public international biomedical research conference on 30th May 2020.

Source: http://www.investinme.org/BRMEC10.shtml#BRMEC10

15th Invest in ME conference – May 30, 2020
"Invest in ME Research has already organised fourteen annual international biomedical research conferences in Westminster, London.

The conferences now attract delegates (researchers, clinicians, media, patient groups, patients, carers, politicians) from twenty countries in a unique international event that is friendly and conducive for learning and networking.

And now our fifteenth conference is taking place in 2020 as the charity embarks on a new initiatives for finding, facilitating and funding biomedical research into Myalgic Encephalomyelitis and increasing knowledge and awareness of the disease.

Our choice of venue reflects our commitment to patients, families, carers, researchers and healthcare staff in providing the best venue for conducting this annual event - now #IIMEC15 (http://bit.ly/2TVaVhx).

Invest in ME Research will be holding its annual Biomedical Research Conference at Westminster's One Great George Street on 30th May 2020

Conference-day registration will be possible from 7.45 and the conference begins at 08.55 on Saturday 30th May 2020.

Please note: Times and presentations are subject to change and Invest in ME Research accepts no responsibility for cancellations, changes to presentations, changes to sequences of presentations or for the timings."

The agenda of speakers is still to be filled in partially and thus still subject to change. The most recent information is to be found here: http://www.investinme.org/IIMEC15-Agenda.shtml

Registration forms can be downloaded here: http://bit.ly/3d5cBwu

Source: http://www.investinme.org/IIMEC15.shtml

ME conference in Stavanger, Norway 23-24th September 2020

This conference will provide an overview of research into ME and clinical care as of today.

This is the second time The Norwegian ME Association - Rogaland County organizes a large conference about ME. Last time was in 2015 with 600 attendees.

We hope many patients, carers, health care personnel and decision makers in health care will be able to join us at this conference as well.

The conference will take place at Radisson Blue Atlantic Hotel, Stavanger.

Wednesday 23rd Sept

The first day of the conference is for health care personnel. All lectures will be in English. Tickets (http://bit.ly/33nuFh7) (in Norwegian)

Thursday 24th Sept

The second day is for everyone. Lectures will be in English, Norwegian and Swedish. Tickets (http://bit.ly/39V9SDW) (in Norwegian)

For further information, ticket requests from abroad, or other enquiries, please send us an email to me.rogaland@hotmail.com

Main speakers

- **Dr. Ronald W. Davis**, Stanford University
- **Dr. W. Ian Lipkin**, Columbia University

Lecturers

- **Øystein Fluge**, MD, Haukeland University Hospital
- **Kristian Sommerfelt**, Professor, MD, Haukeland University Hospital
- **Per Julin**, MD, Karolinska Institutet and Stora Sköndal
- **Nigel Speight**, MD, UK
- **Brian Hughes**, author and Professor in psychology, National University of Ireland, Galway
- **Katarina Lien**, MD, Oslo University Hospital
- **Inger Kristin Lognvik Vestergaard**, MD, Stavanger University Hospital
- **Johan Aske Lund**, MD, Stavanger University Hospital

Source: http://bit.ly/33mXZ7v
All info in Norwegian to be found here: http://bit.ly/33qtjCo

14. Poem - One Stupid Dot

One stupid dot
ME & M.E
Same letters
    separated by a dot.
one's who I am
    one's what I've got.
one's who I used to be
    one's what I'm not.
oh, I'm still ME:
    there's just a dot in between.
But it's a dot that can stop you
    from living a dream.
It's a dot that separates
    the M from the E
And while it's set there
    it's hard to be ME:
the ME I was in healthier days
before the dot came forcing
    the parting of ways.
I'm nothing as M
    and empty as E
But side by side again I could be ME.
That dot has got a lot to explain:
how can something so small
    cause so much pain?
So much devastation?
Seems endlessly cruel.
It's just one stupid dot after all.
Why does it have to be stuck in the middle
    causing complex symptoms
    that read like a riddle?
I have to believe that just as it came
    the dot will mysteriously vanish again.
Every night before sleeping
    I hope and I pray
that I'll wake up as ME
    without a dot in the way.

chill

View the recitation of this poem here: https://youtu.be/M4Nouxub7LU
Stacy Hart aka @MamaChill,
hiphop /rap artist, diagnosed with M.E. in 1991.
Stacy still has M.E., 2 years after being diagnosed

15. Column - Almost of Epic Proportions

A few weeks ago I made it to the beach.

This adventure is almost of epic proportions.

During the past year I rarely left my home, only on very few occasions have I left my town. Once in March, twice for Physio during the summer.

The beach is only half hour away. I longed to see it. With dear friend Pascale, we booked an apartment for two nights as close to the seaside as was possible. It was all a big adventure, and one I wasn't sure I could manage.

After the half hour journey I had to rest. My friend rearranged the furniture in our 'retreat' so we could both have a couch and see the sea.

There is only a lawn between the apartment and the beach. Yet, getting to the actual beach was not within my reach that first day.

The following morning the skies were blue. I had assistance to wrap me up in as many layers as was possible. We drove/walked over the grass to the edge. The beach close, and yet so far.

Pascale had found a little cove the day before. I got out of my chair, slid down the grass, and down onto the beach. I made it! I was grateful. I was sitting on the the beach. The first time in a few years.

I cried.

Such a simple task, which takes such an enormous effort. As I was in pain sitting unsupported, we dismantled parts of my wheelchair. So I sat on my cushion, and had the backrest leaning against the bank. My feet were support with little mounds of sand. Joy so close to tears.

The pain from this adventure has not yet dissolved, three weeks later. But I am forever grateful to have been on the beach and to know I can leave my home, although it comes with payback...

Corina Duyn

Source: http://bit.ly/3cNGBNz

16. Connecting You To M.E.

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

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

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

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