The ME Global Chronicle

www.let-me.be

 # 34 –December 2019

1. Colofon / Personalia

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

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

2. Table of Contents

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

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

3. Editorial

Dear friends,

The voice of the patient continues to be a vital component for bringing the desired recognition, research and treatment of myalgic encephalomyelitis in the coming year. We hope to contribute to it through this magazine of which we here present its 34th issue.

Two petitions are highlighted in this issue.

While each country has unique issues due to the varying health agencies, there is a universal issue of ME being recognized as described by the experts in the International Consensus Criteria. The US petition asks for the US government to recognize this patient group and can be signed by anyone in the world.

- United States- #PwME4ICC Demand US Health Agencies Recognize Myalgic Encephalomyelitis as Defined by ICC
- Dutch ME-patient Evelien van den Brink presented the European Parliament with a petition to recognize ME as a biomedical disease and to allot considerable funds to ME-research based on the CCC/ICC. The parliament decided to prolong this petition and it can still be signed by all European citizens. To make it a bit easier, on lists to be mailed. On each list 6 persons can sign.

Find both under the heading "Petitions"
Furthermore there are lots of abstracts of recent research being published, ME news from many countries as well as news on grassroot activities.

Deadline for next issue (March 2020) is 15th February, with publication around March 22. Please submit articles to contribute@let-me.be (preferred format is in Word using Verdana 12 font).

There is a lot to read in this issue. To make it easier, we recommend picking your choice in the Table of contents and click on the article. At the bottom of each page you can return to the Table of contents.

We wish everyone a better new year in the hope research is going to lead us towards a biomarker or at least better treatments.

January 2020,
The editors
Colleen Steckel
Eddy Keuninckx
Rob Wijbenga

Please do contribute any article or suggestion at any time via contribute@let-me.be

4. NIH/CDC/HHS


NIH
National Institutes of Health
CDC
Centers for Disease Control and Prevention

NIH Funding for ME Needs Life Support

Fiscal year 2019 is over, and we can now examine how much NIH spent on ME research.

In previous years, I've broken down the funding at a granular level. I have done that in a separate post (https://bit.ly/2FcTNfl) for those who want the details. But as I analyzed the numbers this year, I realized that funding for investigator-initiated research needs immediate life support, or the future of ME research is grim.

Bottom line: Funding for individual grants has dropped 25% since 2017. To understand why this is a problem, we need to start by understanding the different ways NIH spends and counts research dollars.

For our purposes, NIH research spending on ME research falls into three categories. First, there is investigator-initiated research, which means a researcher receives funding for a specific project. Second, there are the Collaborative Research Centers created in 2017. These Centers are conducting multiple projects and building research infrastructure. Third, there is intramural research done at NIH itself, such as the Clinical Care Study (https://bit.ly/2Ql02Eh).

NIH adds these three categories of spending together and reports funding as a single number. That annual funding number is what NIH focuses on publicly, such as in the Categorical Spending Chart (https://bit.ly/2Fbo1za) or in the NANDS Working Group Report (https://bit.ly/35g4ckP). NIH points to increases in the number as evidence that it is improving ME research. When the number goes down, NIH frequently blames it on a low number of grant applications.

In 2018, NIH spent just under $12.8 million on the three categories of research spending (see note 1). In 2019, NIH spent $12 million on two categories: investigator-initiated research and the Collaborative Research Centers (see note 2).
The change from 2018 to 2019 is relatively small: a decrease of about 6%. That sounds pretty good, right? If we look at the total amount NIH has actually spent in the last five years on ME, we see this:
Obviously, 2017 was the high watermark of funding because it was the first year of the Collaborative Research Centers. Yet even with the decreases since then, spending is still substantially more than before the Centers were created. That should be good news.

However, focusing only on the total spending ignores where the money is going. When I examined the different types of spending, I found that the investigator-initiated category has dropped sharply since the Collaborative Research Centers were created. In 2017, NIH invested $6.1 million in investigator-initiated grants. In 2019, NIH invested $4.6 million (same as in 2018).

That is a drop of 25%. In fact, investigator-initiated funding is at its lowest since 2012.

You might be wondering: If NIH funding overall is increasing, what difference does it make if the money is going to the Collaborative Research Centers instead of investigator-initiated grants? The answer is that it makes a huge difference, not only right now but it could have dire long-term consequences for ME research.

A healthy research ecosystem needs diversity in ideas, personnel, and scientific approaches. We cannot predict where the best ideas or breakthroughs will come from. For example, in ME research, not everyone should be investigating the immune system. We need projects on neurology, dysautonomia, metabolism, and so much more. We need early stage investigators, and mid-career, and established experts. We need the longstanding giants and people who are new to the field. We need collaborative teams and we need individual labs. When all of these elements are in balance, and there are adequate resources, the research field can thrive.

Since 2017, NIH funding has emphasized the Collaborative Research Centers over the individual investigator grants. NIH points to the benefits to the Research Center model, with multiple projects organized around a central theme and research group. **Dr. Koroshetz** explained in 2017 (https://bit.ly/35dCaXj) that the Centers are not the solution but seeds (https://bit.ly/2SMWWui) that will eventually grow the research.

There are two big problems with this approach. First, and most obvious, is that this approach takes time that we do not have (https://bit.ly/36dG7fP). The second problem is the negative consequences of concentrating resources at three institutions rather than supporting a wider portfolio of research.

We already face a severe scarcity of resources in the ME research ecosystem. For thirty years, we have not had enough money, and so we do not have enough scientists or institutions involved in research. When NIH funded the Collaborative Research Centers, it added new money to the field but it is concentrated primarily at Columbia, Cornell and Jackson Labs. These three institutions alone received more than 57% of the entire 2019 spending. In the short term, that means those three Centers are doing the most NIH funded research, training new investigators, and publishing data.

However, as investigator-initiated funding falls, then the ME field increasingly narrows down to those three Centers and collaborators. That means an individual investigator who is not at one of those three places could have a harder time getting funding. We will lose the diversity of ideas and scientists and trainees that come from funding many different labs. Unfunded investigators will leave the field.Our pool of experts for grant review will shrink further. The Centers can do a great job training early career scientists, but if those investigators can't get funding to start their own labs, they will probably leave the field too.

Concentrating resources disproportionately at the Centers is also dangerous because it leaves the field vulnerable to crashing. NIH funded CFS research centers in the 1990s. By 2003, that funding was terminated, the Centers disbanded, and overall funding dropped 23% in a single year. Today, the Centers represent such a huge proportion of the research portfolio that if NIH decided to terminate them tomorrow, our funding would drop by more than 60%.

We need the entire ME field to grow, but not at the expense of one type of funding over another. ME research needs the Collaborative Research Centers AND investigator-initiated funding. The significant drop in individual grant funding since 2017 is a sign that we need life support, not patience while NIH waits for the Centers to stimulate the field.

NIH is a large institution, and large institutions don't change course on a dime. But sometimes it seems like very few people at NIH even recognize the need for significant change. A case in point is the NANDS Working Group report (https://bit.ly/2sxjLYe). The Working Group spent a year creating the recommendations in that report, and not a single one addressed the urgent need for more funding. (Read my hot take on that report - https://bit.ly/2tsoslV)

Cort Johnson reported (https://bit.ly/2FgcgHC) that after the Advisory Council of NINDS voted to accept the Working Group report, several members of the Council told **Dr. Vicky Whittemore** that, "they had no idea ME/CFS was so underfunded, that so little research had been done, and that such big needs were present."

How? Is? That? Possible?

The NINDS Advisory Council voted to approve the concept of the Research Center RFA. The Council voted to create the NANDS Working Group. This was not the first time Council heard about ME/CFS or the dire funding situation, not by a long shot. I bet if I went back through the meeting videos, I could find multiple times when it had been discussed in presentations. Furthermore, the Council has previously voted to approve funding for ME grants (every Institute Council votes on grants). So how is it possible that Council did not know?

NIH consistently says that they do not receive enough grant applications, and that the ME community must do more to stimulate research. However, the burden of increasing research funding should not be placed on the people with the disease. NIH's neglect and, in some cases, active disbelief of ME has led to the situation we are in today. NIH must take all necessary steps to correct it.

This is an extraordinary situation, and one that is very much of NIH's own making. NIH's persistent failure to invest the resources necessary to grow this field is how we got here. NIH needs to fix this. It is patently obvious that the field needs more Requests for Applications with set aside funding. We know that RFAs attract an increase in applications.

We cannot afford to wait for the Centers to stimulate more applications five, ten, or twenty years from now. We need more funding now. We need more Research Centers now. We need more investigator-initiated grants now.

NIH is not doing enough. The NANDS Working Group report is not enough. (https://bit.ly/2tmxb9l) NIH's current investment in ME research is not enough (https://bit.ly/2Fgcs9O). **Dr. Koroshetz** and **Dr. Collins** could be heroes. They have a chance right now to stop the research free fall and get us back on the right track. They have to do this, or people with ME will suffer even more.

Jennie Spotila
https://bit.ly/2QflFFQ

5. Dutch Citizen Initiative

The Dutch Citizens Initiative and Its Longterm Consequences

There are important developments happening in the Netherlands that could drastically turn around the attitudes of various governments towards ME research and clinical practices.

As has been reported from the beginning of the creation of the ME Global Chronicle, a civil initiative (CI) started in 2011, which has been extremely successful and in 2015, 56.000 signatures were handed to the Dutch parliament.

In the end the CI was declared admissible and the Dutch Parliament ordered the Health Council to evaluate and draw up opinions on the position of ME and its patients in the Netherlands. This process was completed on March 19, 2018, and the final report was handed to the permanent committee of the health department of the Parliament (HWS) https://bit.ly/2SQe2Hu

In the Netherlands, the minister is responsible for implementation of the policy, but they are monitored by the permanent HWS-commission. The petitioner, Groep ME –Den Haag (Group ME-The Hague), had offered research proposals outside of ZonMW, which is usually tasked by the minister to execute such orders. But during a previous course, ZonMW were guilty of involving themselves in a conflict of interest. In addition, the preparation for and execution of a research program takes more time and money. Aside from that, we have to wait and see if ZonMW will lend any substance to the task of letting patients participate.

On March 7, Groep ME-Den Haag along with 3 other patient organizations had a conversation with members of the minister’s staff, in which it became apparent that the proposal from Groep ME-Den Haag had been bypassed. Without consulting any of the patient advocates the task had already been assigned to ZonMW. That will most certainly be addressed.

On March 27, a discussion took place between Groep ME-Den Haag with 4 patient organizations and the permanent Health Council committee, during which the actions of the minister were undoubtedly addressed as well.

During the rest of the year ZonMW held meetings with 4 patient organizations, among which the petitionary: Groep ME-Den Haag. This culminated in a plan of action which was only partially supported by Groep ME-Den Haag due to core elements missing from the CI. The Health Council's report from March 2018 clearly states that international expertise should form the basis for future domestic research. After all, ME remains pretty much unexplored in the Netherlands as a result of its psychiatric approach, which has held the reins for decades after having followed in the UK's footsteps.

Questions from MP's to the minister have severely sped up the process of establishing a research agenda. Severely, seeing as input from groups like Groep ME-Den Haag hence risks falling into the void, considering the group consists exclusively of severely ill ME patients.

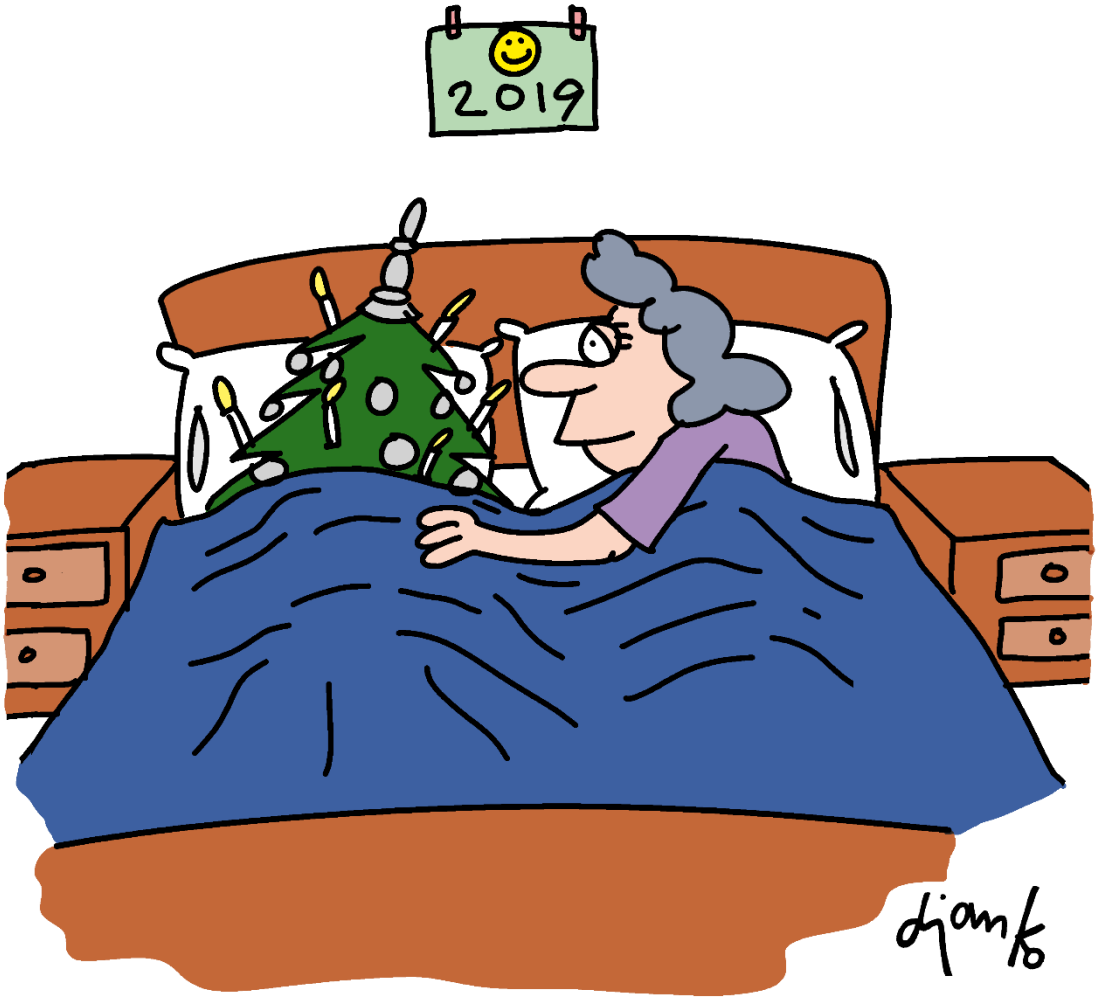
Next phase is to be implemented this year: ZonMW has appointed a steering group tasked with compiling a research agenda. Here, too, any available expertise on ME is yet to be referenced, and as such, Groep ME-Den Haag has acted in protest against this.

Refusing to be a participant of the steering group is not an option however, so Groep ME-Den Haag is counting on their suggestions finally being heard after all, supported by a letter from 76 international ME researchers and clinical experts.
Right now, the minister concerned wants to present a research agenda with budget to the parliament before the summer vacation.

It is crucial that the nature of the research needs to be completely biomedical, must be compatible with the international scientific standard in regards to matters regarding ME and patients must participate. Groep ME-Den Haag will continue to keep a close eye on that.

To be continued.

Cartoon Djanko



6. Grassroot

Myalgic Encephalomyelitis – Getting A Diagnosis

Aka "Diving down the rabbit hole."
Since the London Royal Free Hospital outbreak in 1955 and the World Health Organization added ME to the neurological disease section in 1969, the story of this disease looks like a chapter from Alice in Wonderland.

Finding our way back through the looking glass involves going back to the basics of how to get a proper diagnosis.

The Myalgic Encephalomyelitis International Consensus Criteria (ICC) published in 2011, is the most recent ME criteria and in conjunction with the information in the ME IC Primer for Physicians, doctors are able to make a much more reliable diagnosis than what patients have been getting.

From the ME IC Primer:
"Remove patients who satisfy the ICC from the broader category of CFS. The purpose of diagnosis is to provide clarity. The criterial symptoms, such as the distinctive abnormal responses to exertion can differentiate ME patients from those who are depressed or have other fatiguing conditions. Not only is it common sense to extricate ME patients from the assortment of conditions assembled under the CFS umbrella, it is compliant with the WHO classification rule that a disease cannot be classified under more than one rubric. The panel is not dismissing the broad components of fatiguing illnesses, but rather the ICC are a refinement of patient stratification. As other identifiable patient sets are identified and supported by research, they would then be removed from the broad CFS/CF category."

Link to IC Primer: https://bit.ly/2rXKxbR

In an effort to aid patients (and their doctors) the North Carolina/Ohio ME & FM Support Group has created a list of diseases that should be ruled out or checked for as comorbid conditions.

Getting a diagnosis is just the first step. All patients need doctors to take the necessary follow-up steps to confirm a diagnosis. Unfortunately, what we are seeing is a "label and send home" approach around the globe. Patients who are suffering from diseases that have treatments are needlessly suffering.

Link to list of diseases to rule out: https://bit.ly/35tZktt

Colleen Steckel
Founder North Carolina/Ohio ME & FM Support Group (on Facebook)

Note: This is a collaborative document and input is welcome.

Myalgic Encephalomyelitis Resource Materials Now Available In Spanish And Dutch

MEadvocacy.org understands the challenges faced by ME patients are a worldwide problem and we appreciate volunteers translating materials.

Spanish:
Thanks to the help of La Plataforma de Enfermos de EncefalomielitisMiálgica the following resources are now available in Spanish at: https://bit.ly/36G8KlC.

Simple ME Fact Sheet – Aspectos Básicos Sobre Encefalomielitis Miálgica
https://bit.ly/2Pt8vob

Brief ME History - Breve Historia de la Encefalomielitis Miálgica (ME)
https://bit.ly/34qF2Qc

"What is ME" handout - ¿Qué Es Encefalomielitis Miálgica? https://bit.ly/2EmrKtr

ME Science Links-- published studies on myalgic encephalomyelitis - Enlaces CientificosPublicaciones de Encefalomielitis Miálgica https://bit.ly/2EvYT5H

Important ME Quotes – Citas importantes sobre Encefalomielitis Miálgica (ME)
https://bit.ly/2EooLjU

La Plataforma de Enfermos de Encefalomielitis Miálgica can be reached at plataforma.eem@gmail.com.

Dutch
Thanks to ME/cvsVereniging (https://www.me-cvsvereniging.nl/) for translating the ME ICC Questionnaire into Dutch. https://bit.ly/2RYvPfi

- Note: The public may freely share these sheets created by MEadvocacy.org as long as the document is not altered, and MEadvocacy.org is credited.

Proper recognition of ME is a global issue and we hope providing these resources helps to raise awareness about the reality of Myalgic Encephalomyelitis.

These documents and the English versions, as well as additional important information, may be found on the 'RESOURCES" tab here:
https://www.meadvocacy.org/resources

Personal Insights

Personal Insights: Only illness allowed me to see the Imperfect Perfectness of life

Galway woman, **Marie Hanna Curran**, in this 'Personal Insights' submission reveals how her battle with illness has finally allowed her to appreciate the joy of life.

AS is often the case within the span of a small life, control was suddenly taken from me when life decided to yell at me and push me in the right direction - knowing if she didn't - I'd never get there. While my feet moved backwards on life's chessboard, my mind, being one of logic and linear thinking, cursed and screamed. After all, who moves backwards in this life of ours?

The losers.

I was a winner. I'd graduated university with a degree, I'd worked for a multinational company in finance. I'd bought a home, I was married and was earning a good wage. Socially I had a good life too, there was the local athletics club and there were races and even a marathon. The boxes were ticking themselves off, and so I was winning.

I was winning until I lost.

My illness wasn't something I'd really known about, it's two shortened letters, ME, meaning little to me until they arrived at my door, knocked down the door and walked themselves right in. Once they were in, they sat on my couch, slept on my bed and sat beside me at my kitchen table as I began sleeping and resting and pacing so as to keep my symptoms of headaches and nausea and muscle pain and bone pain and constant fatigue at bay.

My social life was the first to go, then my running and sure enough my work soon followed, as did my house proudness. Everything was condensed, reduced and as I saw it, lost. During my first year of illness I did as any losing side does. I fought. I wanted back on that path, back in the past, back on that winning team but the more I fought the more I lost.

There were no known treatments for me so I tried a few anyway. There was a drug which made me worse. There was a therapy which made me worse and there was a strict diet which didn't make me worse but equally didn't make me any better. All the while those around me were on the opposite side of the playing field. They were climbing ladders at work, travelling, socialising, and reaping the rewards of hard work in the form of additional mortgage payments and updated cars. As they continued winning, I continued sitting in my stinking stagnant pond, losing.

Then, somewhere into that first year I stopped losing.
One morning I got out of bed and stared down the mirror at ME and told those two little letters they could sit beside, stare at me and envelope me but they would never become me.

Slapping myself and vowing to end all ridiculousness I decided I was no longer sick with ME but rather living with ME. Funny to think the rearrangement of a sentence can have such a life altering effect on someone, trust me it can. From that day on, I began living my new altered life. One away from consumerism and toe tags and lists and must haves and must dos. Suddenly I was free and realised losing isn't always bad.

Those coins down the back of the couch and that sock in the washing machine. They're never lost, just misplaced. And so I realised while I was stuck with this life altering, life limiting illness, I didn't lose my past, instead, I found my path. Over the coming years I reimagined my life. First was myself. I threw out the excess clothing and bags and shoes. I donated anything without purpose and happily made do with all that I had.

Then I threw social media into the bin and limited my internet usage to reading the news as friends, family and neighbours kept me connected with all I needed to know. What followed next was the garden, a ¾ acre plot of green which had been idle for years. A garden who's planting began with fifteen friends and their shovels and gifts of shrubs and my very first tree. A blossom tree.

After that first bed, a bed known as the birthday garden, there were gradual additions and so five years on a forest is slowly developing with over one hundred native trees and a small garden pond. No matter the day, no matter the season, every window within my home offers up a kaleidoscope of delights and a bench outdoors allows an even closer view of those living within the bounds of this babbling patch. Bats, herons, tits, finches, blackbirds, thrushes, robins, wagtails, foxes and even a pine marten have been spotted going about their daily lives.

My home once used to scrub, to clean, is now used to watch the sunrise and sunset and each of these gifted delights. As with all paths, there were further steps. There was the addition of fifteen raised vegetable beds and fruit bushes and two laying hens. A once devoid piece of lawn has been transformed into a wildlife haven, a food source and a space in which I can amble and potter.

Nothing on this path has been planned or intentional and yet it's far more rewarding than the path of my past.

I've come to learn what's important and what's not and most of all, I've learned there are no such things as planning the perfect.

Only imperfections exist in this world and we are one of those tiny imperfections. Each of us hoping to do something useful with our imperfect existence before we're forgotten.
The End

Source: https://bit.ly/2PvHccM
Monday, November 11, 2019 - 06:26 PM

#MEAction: Join #MEAction's Board of Directors

Dear friends,

#MEAction is building a global movement to fight for recognition, education and research so that one day, all people with ME will have access to compassionate, effective care.

We are currently seeking patients, caregivers, and allies with one or more of the following experiences to join our Board of Directors:

- Have built and led non-profit boards
- Have scaled young organizations particularly social and business startups
- Have raised money, particularly grant-making, private giving, foundations, and family offices
- Have demonstrated leadership in business, non-profit, government/politics, and/or health research, policy or care organizations
- Have organized at the grassroots level, built distributed organizations, movements, and/or networks

Based in Los Angeles, #MEAction was co-founded by **Jennifer Brea**, director of the Sundance award-winning, Emmy-nominated documentary Unrest.

The Board consults the organization's Executive Director in all areas including operations, communications, finances and development.

Candidates should have experience volunteering for a nonprofit organization and a passion for #MEAction's mission. The Board of Directors meets monthly virtually and once a year in person.

Board members from the United States, United Kingdom and Australia are especially encouraged to apply.

Please email Co-chair of the Board, Pam Laird with a resume and letter of interest at pam@meaction.net. Use the subject line: "Board of Directors 2019."

About #MEACTION

#MEAction is building a global movement to fight for recognition, education and research so that one day, all people with ME will have access to compassionate, effective care.

We are an international organization that develops and supports a network of country affiliates, affinity groups, city, state, regional and other local chapters, and individual advocates. We are people with ME, caregivers, family members and allies. Learn More: https://bit.ly/2EVAvuv

About Our Founders

Jennifer has an AB from Princeton University and was a PhD candidate at Harvard in political science and statistics until a sudden illness left her bedridden. In addition to her work with #MEAction, she directed the Sundance award-winning documentary, Unrest.

Beth earned her Bachelor's in Computer Science and Electrical Engineering from MIT. She is interested in how to best use technology to empower ME patients and achieve health equality. She worked as a developer and technical product manager for various for-profit and non-profit technology companies including the Grameen Foundation and Jaspersoft.

Learn More:

- Meet our Board https://bit.ly/2EZxRUC
- Learn about our vision and mission https://bit.ly/37butSL
- Visit: http://meaction.net https://bit.ly/2ZxLxzU
- Watch Jen's TED Talk https://bit.ly/2Zzcm6D
- Watch Jen's Sundance award-winning film, Unrest https://bit.ly/2Qm8AcJ.

Join us in building a global movement for ME!

Marathon Mike

Porto (Portugal, 03.11.19)

Porto marathon was my last of 2019 and came just 3 weeks after Bucharest taking it up to 6 races for the year. Ahead of the race I'd managed to secure a feature on a top Portuguese sports website and interviewed 3 M.E sufferers to find out what life was like there. **Cat** and **Lucy** were back with me, a day after **Lucy**'s 1st birthday party with family near to our flight from Gatwick. We landed at around 3.30pm and stumped up the cash for a swift taxi to our apartment before a slightly hairy walk through a rough part of town to the Expo. I grabbed my race number with an hour to spare and we trudged around downtown Porto through the driving rain to find dinner and then (with surprising difficulty) a shop that sold bananas and cereal bars.

Start

After a rough night of about 4 hours sleep due to an unsettled **Lucy** and an outrageously loud nightclub opposite, we took the long metro up to Matosinhos Sul, North West of the city centre. It was cloudy and cool as I crossed the start line to the sound of **Bon Jovi**'s 'Living On A Prayer'. I really enjoyed tracking the Atlantic Ocean, the sea was pretty wild and the beach of Praia De Matosinhos was empty. With around 4000 marathon runners and many more with us running the 'family run' 15km it was tough getting into a good stride for the first couple of miles.

(read more https://bit.ly/2QjRTi0)

Mike

Progress in Germany!

As reported by ME-patient **Katharina Voss**

Progress! The German "Pschyrembel", a medical glossary and the most important German reference book for doctors and medical students, adopted the International Consensus Criteria (ICC) (https://bit.ly/2Puek4Q)

Except the name (they still use Chronic Fatigue Syndrome) the author **Prof. Dr. Hermann Füeßl** wrote a very precise record on Myalgic Encephalomyelitis, mainly based on my book on ME (https://amzn.to/2rUdipQ)

From the article on ME in Pschyrembel:
Classification: according to International Consensus Criteria (ICC)

- Mild onset: Activity level reduced by 50% compared to before the illness Moderately ill: Patients are mostly tied to the house
- Seriously ill: Patients are predominantly bedridden
- Very seriously ill: Patient is completely bedridden and unable to carry out hygiene measures independently

Pathophysiology:

- Dysregulation of the nervous system, immune system and cardiovascular system, at the cellular level disturbances of energy metabolism and ion transport.
- Numerous disorders at the immunological, neuronal, hormonal and cellular level described, but not all disorders detectable in all patients.
- Disturbed immune regulation: e.g. sustained T cell activation, diminished natural killer cell function (so-called low-natural killer cell syndrome, abbreviation LNKS), lack of immunoglobulins, deficient EBV-specific B memory cell and T cell response
- Neuronal abnormalities such as reinoinflammation in extended brain areas, markedly reduced white matter (indicative of chronic inflammatory processes), deformation of the right arcuate fasciculus, and thickening of two areas of gray matter in the immediate vicinity of the nerve cord (expression of the deformation correlates with severity of clinical symptoms)
- Blood flow to the brain stem and cerebral cortex reduced.
- Disruption of mitochondrial function with lack of ATP Disruption of AMP kinase activation and glucose uptake in muscle cells.
- Autoantibodies to thyroid proteins, neurotransmitters, and receptors (eg, beta-adrenergic and muscarinergic cholinergic receptors).

Triggering factors:

- Mostly viral infection, eg. B. Epstein-Barr virus (especially in late first infection), enterovirus, dengue virus, herpes simplex virus-1, human herpesvirus 6, influenza.
- Less common: bacterial infection (Q fever, Lyme disease, Chlamydia, Legionella).
- Often unspecific respiratory tract infection.
- Questionable XMRV (xenotropic murine leukemia-virus-related retrovirus) - has not been confirmed in several studies.
- Other previous events such as pregnancy, accident (especially cervical spine trauma), surgery or critical life event such as death of a relative, unemployment, military combat mission.

Disease-sustaining factors

- Overload (physically, mentally, psychologically)
- Lack of social support
- (further) infection, surgery, accident
- Reactive depression.

Update On The Classification Of PVFS, ME And CFS For ICD-11

In this important update on ICD-11, **Suzy Chapman** writes: "Please note that I have retired from active advocacy work around classifications and coding. It is crucial that advocates, patient groups and their professional allies inform themselves, become confident around the various classification and terminology systems and take responsibility, as stakeholders, for submitting timely responses and requests for changes, because I shall no longer be doing this work."

The International Classification of Diseases 10th Revision (ICD-10) is the global standard diagnostic classification of diseases for use in epidemiology, health management and clinical practice. ICD is maintained and published by the World Health Organization (WHO). How disease terms are classified has implications for commissioning of services and may negatively influence the perceptions of researchers, clinicians, allied health professionals, medical insurers and agencies involved with benefits assessment, provision of social care, access to disability adaptations and workplace and education accommodations.

The next major revision of ICD (ICD-11) has been in development since 2007.
In June 2018, the WHO published a stable version of ICD-11 as an "advance preview" to enable Member States to start planning for implementation of the new edition. On May 25, 2019, the World Health Assembly (WHA) voted unanimously to adopt ICD-11. WHA's endorsement of the new edition won't come into effect until January 01, 2022, which is the earliest date from which Member States can begin using ICD-11 for reporting data.

There is no mandatory implementation date and Member States will migrate to ICD-11 at their own pace and according to their countries' specific timelines, requirements and resources. During this transitional period, the WHO will accept data recorded using ICD-10 or the new ICD-11 code sets.

The progress of the G93.3 terms through the ICD-11 Alpha and Beta drafting stages has been a frustrating and tortuous journey hampered by a lack of transparency and accountability on the part of ICD Revision and an apparent indifference to maintaining effective stakeholder engagement.

How have the ICD-10 G93.3 terms been classified for ICD-11?
Download my report at: (pdf) https://bit.ly/36HqSvu or http://bit.ly/MEGCICD11

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

A Warm Welcome From ME International

ME now has an International Organization!
The purpose of ME (Myalgic Encephalomyelitis) International is to support ME organizations, educate the general public, medical providers, and governments throughout the world, and support ME patients, caregivers, advocates, and family and friends.

ME International is an all-volunteer organization.
All donations or money collected will go directly to people in our ME community that need our help.

It is worth reading the history.https://bit.ly/39GvaFC

There are different criteria for each of these definitions. The most specific criteria for ME is the ICC and the precursor is the CCC. We suggest that everyone with this disease should research the criteria and decide which one matches their symptoms and take that to your doctor and support the organizations that use that criteria.

We don't tell you what to do. It is up to you to do your research. For information about the different criteria click the following link.
https://bit.ly/2rZHlfW

If we had just one set of criteria for ME, we would have a better chance of getting doctors, governments, other organizations to support our cause.

As we all know, right now there is no official cause or cure for this disease. We know we are just beginning, but if we work together it will happen. Now comes the hard part, finding help from these different groups for our Board and Committees. We want this organization to be run by people that really care about this disease and want more than anything to find a CURE! There is no charge to join this organization. If we raise funds in the future it will be for a specific cause managed by our Foundation Committee. All positions are volunteer. We want people to do it because they want to and see the need to help, not for the money.

Everyone can participate at any level and do only as much as they can. Imagine having millions of people that are members of this group....could they still ignore us? Please join us in making this dream a reality! Click the link to join
ME International! https://bit.ly/37CF6hH

If you would like to read my story about why ME International was started, here is a link. https://bit.ly/2MWmD7U

Submitted by **Pam Lutey**

Dr Myhill's Complaint to the GMC About the PACE Authors

The Information Commissioner's Office [ICO] has slapped a Decision Notice on the GMC. The GMC must release the evidence base for its determination not to investigate the PACE authors or admit that there was no evidence base for that decision. If there is no evidence base, then **Dr Myhill** will take the decision not to investigate the PACE authors to the High Court for a Judicial Review.

The GMC has consistently refused to release any evidence base for its decision not to investigate the PACE authors and so one might assume that there is no evidence base!

Summary

- **Dr Myhill** complained to the GMC about the PACE authors
- The GMC determined not to investigate her complaint
- **Dr Myhill** conducted an FOIA search on the GMC to try and determine the reasons for that rejection of her complaint
- When the GMC papers of the above FOIA search were released, **Dr Myhill** considered that the GMC had determined their decision not to investigate the PACE authors based purely on opinion and that there was no evidence base for their decision, or at least no evidence base as released to Dr Myhill under the FOIA search
- **Dr Myhill** then asked the GMC, again by way of a FOIA request, that
    - Either they release the evidence base for their decision not to investigate the PACE authors
    - Or state they had no evidence base for such decision and that indeed their decision not to investigate the PACE authors had been based on opinion only
- **Dr Myhill** considered that the GMC reply to her FOIA request as directly above was inadequate and so complained to the ICO
- The ICO has upheld **Dr Myhill**'s complaint
- The GMC now has 2 options
    - Appeal this decision
    - Answer that either they had no evidence base for their decision not to investigate the PACE authors or release the evidence base for that decision.
- If the GMC fails to do either of the options in previous point 8, they will be held in contempt of court. They have 35 days in which to do so.
- If the GMC cannot supply an evidence base within 35 days for their decision not to investigate the PACE authors, then **Dr Myhill** will take that decision not to investigate to a Judicial Review.

Source: https://bit.ly/2oqr8OM

Doctor Sarah Myhill is a British doctor running her own specialist M.E. clinic in Knighton, Wales, United Kingdom. Her website is an extensive resource of articles and information based on her treatment of patients, it runs to 920 webpages and has had over six million individual visits.

Dr Myhill's view is that Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is characterized by a cellular metabolic mitochondrial dysfunction and has published several studies. **Dr Myhill** has treated in excess of 10,000 CFS/ME sufferers over her 30-year career.

With thanks to ME-pedia https://me-pedia.org/wiki/Sarah_Myhill

Unrest

I am thrilled to share the good news that Unrest has been selected as a 2019 Doc Impact Hi5 honoree (https://bit.ly/2Q1PMQY)!

Unrest was among five documentary films chosen by a panel of industry experts. Honorees "exemplify what can be achieved by filmmakers and impact producers operating in incredibly different contexts, all while demonstrating excellence in filmmaking, as well as creating significant and measurable social impact."

They recognized Unrest as a film that "turned a dedicated community into massive reach that increased awareness and helped build people power."

This is not an award for filmmaking as much as it is an award for IMPACT––the impact you helped make possible.

What you and our partners helped our community achieve was groundbreaking and historic. By sharing the film on social media; talking to your friends and family; showing up in theaters; organizing screenings; donating to #MEAction, the #TimeforUnrest impact campaign, or your local ME organization; supporting research; lobbying Congress and Parliament; and sending postcards to your doctors, you changed the world.

Your hard work has been recognized! A centerpiece of this award is an in-depth (80 page!) case study of the campaign, meant to inspire and inform future documentary films and the movements that can help to propel or create. It also beautifully immortalizes how hard and powerfully you leaned into this precious moment to help us all use the film to create change for people with ME.

Read the case study https://bit.ly/39lzQ3Q

I remain forever grateful and humbled by the faith so many put into this film, starting way back in 2013 with the "Canary in a Coal Mine" campaign; for all the love, sacrifice and investment that went into making it; for how bravely so many shared their stories (especially **Jessica**, **Leeray**, **Casie**, **Karina** and **Whitney**); and how this community gathered around and lifted up this film.

Your dedication and commitment to fighting for yourself and others has been awe-inspiring. I have said it before and I will say it again––the film campaign may have wound down but in its place is a movement, stronger and more powerful than ever before. I truly believe this is only the beginning of the fight for recognition, education and research, and that together, in the coming months and years, we will achieve incredible things.

With love, gratitude, and solidarity,

Jen

In My City

In my city

There is a delicate,
kind sunshine
in this morning
of November
in my city

And I feel
that our sufferings
they will not be lost

They ignored us
mocked us
blamed us
they wanted us to believe
that we were crazy
and instead
we are physically sick

We rebelled
but power was on their side

Yet I feel that our sufferings
our dignity
and empathy
will save those after us

Yes, I know

It’s just a warm
sunny morning
in my city

Lavinia Capogna,
Rome,
Italy

Why We Care

BREAKING: A generous donor has offered a matching donation of five thousand dollars in memory of **Heather Colman McGill**, a severely ill ME/CFS patient who has recently passed away. She was dear to many people in our community. Her presence will be sorely missed.
You can donate here https://bit.ly/2ECBv6K

It's that time of year again. The leaves are falling, and the weather is turning snappy. Soon, families will gather around the table for holiday feasts. We will give thanks that we are together, share the bounty of the harvest, and enjoy the warmth and comfort we feel when those we love surround us.

For people with ME/CFS the holidays present a challenge. Even for those of us who have warm, loving families, it is difficult to rise to the occasion. We are exhausted easily by interactions, no matter how pleasant those may be. We can't talk with our relatives as much as we would like, sit through long dinners with them, and participate fully in family rituals.

The holidays present even more of a challenge for those who have no family to share the holidays with. This is an especially painful time for people whose families have ostracized them.

Kristy's Story

"**Kristy**" is one of the applicants to the AMMES financial crisis fund. She is severely ill, and lives alone. Her father threw her out of the house when she got pregnant and her boyfriend abandoned her. **Kristy** had the baby, but was too ill to care for it, so she was forced to give up her child for adoption. She keeps trying, unsuccessfully, to make her family understand how sick she is.

"They just don't believe me," she told me in a recent conversation. "They say 'Why don't you get up and find a job? You're just lazy.'" **Kristy** is so weak she can barely brush her hair. It takes her days to recover from going to the corner to buy food. AMMES has sent her money for food, but she has still lost fifteen pounds, and she was thin to begin with.

"I'm scared," she says. "I don't think I will survive."

Abandonment and Rejection

Kristy isn't the only person who has applied to the AMMES financial crisis fund for help after being abandoned. Another woman, who I will call **Laura**, was rejected by her family, and worse.

"My brother told me to just kill myself," she told me. "I really don't have family that cares or understands or is safe for me to seek help from. I don't know which is worse anymore, the disease itself and how it hurts me or the hatred and selfish disregard for my life from other people."

Laura is housebound. She can only leave her home every seven to ten days to shop. In between grocery shopping, she rests to recuperate her strength. Life is a continuous battle for Laura.

What we can do

Laura and **Kristy** are just two of the people who have reported ostracism, neglect, abandonment, and outright hostility from family members, partners, and friends. All too often they say that I am the only person they can trust. This is heartbreaking.We all need friends and family members we can trust.

Let's make the holidays joyous for those in our community who have suffered the sting of rejection. Let's include them in our celebrations. Let's give them the gift of caring.

Please donate to the AMMES fall fundraiser. So far, we have given people like **Kristy** and **Laura** over $75,000 in direct aid to help them pay their rent, utilities, medical expenses, food, and other basic necessities. Every penny that is donated will be spent to serve this neglected population.

Our Crowdrise Fall Fundraiser is here https://bit.ly/2s8rOue

Our goal is to raise $10,000. That will see us through the next three months.

You can donate directly to our financial crisis fund here https://bit.ly/2PIedTi

AMMES is a 501(c)(3) national nonprofit. Your donations are tax deductible.

Submitted by **Erica Verrillo**

ME/CFS Alert

Episode 110 - Interview with **Ron Tompkins**
https://youtu.be/He0WOVHVQCw
Ronald G. Tompkins, MD, ScD, is the Sumner M. Redstone Professor of Surgery at Harvard Medical School, Founding Director of the Center for Surgery, Science & Bioengineering at Massachusetts General Hospital, and Chief of Staff Emeritus at Shriners Hospitals for Children—Boston.

Dr. Tompkins has published more than 450 research papers in medicine and engineering journals and has contributed to the advancement of science and engineering through service on institutional advisory panels, moderating mini-symposia and workshops on biotechnology, and studying the genomics and proteomics of immunology and metabolism resulting from injury.

Episode 111 – interview with **Chris Armstrong**
https://www.youtube.com/watch?v=loSrAyKXyuM
Chris Armstrong, PhD, is most well known for his research using metabolomics to observe biochemical alterations in ME/CFS patients. He began his work in this field at the University of Melbourne, beginning a PhD project to apply metabolomics to study ME/CFS and published his first ME/CFS metabolomics study on blood and urine in 2015.

Since then **Chris** has set up collaborative efforts to apply metabolomics to immunological experiments on ME/CFS, observing how metabolism may relate to immune cell function. He has also focused on longitudinal research in ME/CFS while looking to extend metabolic capabilities across the field of ME/CFS to help collate different patient groups.

Chris is working with OMF's communications to translate science for the public while continuing his research as a Visiting Scholar at Stanford University.

Episode 112 – interview with **Linda Tannenbaum**, President and CEO of the Open Medicine Foundation.
https://www.youtube.com/watch?v=Y6NdyrNqvF4&t=237s
In the interview, **Linda** talks about her work and her ambitious plans for the future of funding ME research. I've always been impressed with her leadership and single-mindedness. The dedication of people like **Linda** is a shining and beautiful thing. My hope is that we'll see a day when they don't have to do what they do so tirelessly.

Llewellyn

Solve M.E. Webinar

Solve M.E. Webinar presented by **Dr. Amy Proal**: ME/CFS in the Era of the Human Microbiome

The neurological illness ME/CFS has been repeatedly tied to infection with persistent pathogens such as enteroviruses, Epstein Barr Virus and other herpesviruses – and there have been outbreaks of the condition over the past decades.

In this webinar, **Dr. Proal** (Autoimmunity Research Foundation) discusses how expanding research on the human microbiome now allows these and other ME/CFS-associated pathogens to be studied as interacting members of vast human microbial, viral and fungal ecosystems in tissue and blood. The presentation outlines key mechanisms by which pathogens in these communities – and the proteins/metabolites they create – can control human metabolism, gene expression and immunity in a manner that may contribute to ME/CFS symptoms (with symptoms varying based on a patient's unique infectious and environmental history).

Dr. Proal also discusses a collaborative project sponsored by the Solve M.E. Ramsay Research Grant Program (https://bit.ly/37rA5IH) to identify known and novel organisms in ME/CFS blood and cerebrospinal fluid, and current Alzheimer's research at Harvard University that is shedding light on how persistent pathogens in human brain tissue can drive neuroinflammatory symptoms.
Watch the webinar here: https://youtu.be/Y9G-6MGcSh8

Ramsay Grant Program

2019 is our biggest year yet! We have over 30 researchers working across seven projects. The group represents 12 academic centers and organizations. Three of the studies will be done collaboratively, integrating scientists from different labs.

Here they are:

- "Altered T cells in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)" - **Liisa Selin** (PhD) and **Anna Gil** (PhD)
  University of Massachusetts Medical School https://bit.ly/2SN4k94

- "Possible class II MHC deficiency in patients with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS)" - **Bruno Paiva** (PhD) University of Navarra, Spain
  Collaborators: **Manuel Ruiz Pablos**, **Rosario Montero Mateo** (MD), **Aintzane Zabaleta Azpiroz** (PhD), **Diego Alignani** (PhD), **Idoya Rodriguez Serrano**, **Sonia Garate Luzuriaga**
  https://solvecfs.org/bruno-paiva

- "Defining the postural contributors to post-exertional malaise (PEM) in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)" - **Shad Roundy** (PhD), University of Utah
  Collaborators: **Cindy Bateman** (MD), **Turner Palombo**, **Andrea Campos** https://solvecfs.org/shad-roundy

- "Extensive characterization of the ME/CFS blood and CSF microbiome + virome " - **Nikos Kyripides** (PhD), **David Paez-Espino** (PhD), **Kris Fobes** DOE Joint Genome Institute and the Lawrence Berkeley National Laboratory; GeneSavvy
  Collaborators: **Amy Proal** (PhD), **Jonas Bergquist** (MD, PhD), **Robert Moir** (PhD) - https://bit.ly/2ZGIUf8

- "Unraveling endothelial function in ME/CFS"- **Francisco Westermeier** (PhD) FH JOANNEUM University of Applied Sciences, Austria
  Collaborators: **Nandu Gowami** (MD, PhD), **Nuno Sepulveda** (PhD), **Monika Riederer** (PhD), **Bernhard Wagner** (PhD), **Jennifer Blauensteiner** (PhD) https://solvecfs.org/francisco-westermeier

- "PARsing post-exertional malaise: does post-exertional autonomic recovery (PAR) impact post-exertional malaise?"- **Kegan Moneghetti** PhD, MBBS (hons), FRACP, Stanford University
  Collaborators: **Lily Chu** (MD, MSHS), **Jeffrey W. Christle** (PhD, CEP), **Donn Gavert** (MS), **Tullia Lieb** - https://solvecfs.org/kegan-moneghetti

- "Brain perfusion changes in chronic fatigue syndrome before and after exercise challenge" - **Michael Van Elzakker** (PhD) and **Kenneth Kwong** (PhD) Massachusetts General Hospital, Harvard Medical School
  Collaborator: **Suk-tak** (Phoebe) **Chan** (PhD) - https://bit.ly/2SHPTmB

Research Participants

I've observed a couple of trends that I would like to share.

Firstly, I am finding less "open" studies where sufferers from anywhere can participate - instead I am starting to see more studies where the research team is recruiting from specific hospitals/locations.

Secondly, there seems to be more research collaboration, with larger, coordinated research teams; I believe more collaboration and coordination will take us further, faster.

Regarding my effort to entice researchers to pool some funds and fly several ME sufferers to a central examination location, a few thought it was a good idea but so far no commitments.

Also, I've begun collaborating with Action CIND (https://www.actioncind.org) by joining their board of directors. Action CIND is committed to advancing ME research in Canada. You will likely be interested in attending some of their informative webinars. Past webinars can be viewed on website Vimeo.com - search for “Action CIND”. Please let me know if you'd like to receive their newsletter.

I hope you've had some positive things go your way this year. I will continue to search for ME research studies - hopefully one will be suitable for you to participate in.

Take care and I wish you peace in 2020.

Mike
michael_lapenna@meresearch.info

In Memoriam: Heather Colman-McGill

Heather Colman-McGill 1981 – 2019
In celebration of a beautiful soul –tribute by **Amber Ella** and **Christina Steiger**
Heather Colman-McGill, a vibrant environmental scientist, friend, daughter, sister, partner, advocate, and activist has died after fighting for her life for years with very severe myalgic encephalomyelitis (ME).

Before ME, **Heather** led an active life as an environmental scientist, athlete, and world traveler. She had a deep love of nature and the environment and a tremendous zest for life. Before falling ill, she took every opportunity to be outside and enjoy the natural world. She loved all life on this beautiful planet and was a staunch advocate for biodiversity.

Heather first developed ME as a teenager, though like many patients, she was not diagnosed for nearly 20 years. In her case, she was infected by a tick-borne disease at 12 and mononucleosis at 18 and was exposed to toxic mold in her childhood homes and schools. She began having many symptoms of the illness, but when doctors had no answers, she simply pushed through until that was no longer possible.

Despite declining health, **Heather** managed to earn a BA in Biology at Bowdoin and a Masters in Environmental Management at Yale. **Heather** hoped for an exciting career working as an environmental science and policy expert. In her last position, she worked as a UN consultant on biodiversity loss, protected area management, and climate change. Despite her illness, she remained passionate about environmental policy. She wanted nothing more than to step back into her life and career. It was with great pain that she could not be on the front lines of the fight against climate change, yet she still found ways of raising awareness, even as her health continued to fail.

Now, at age 38, **Heather** is gone.

The world of severe ME is unimaginable to most. She could rarely experience the outdoors on her "good days" if carried out in a wheelchair in a reclining position, as even sitting up briefly was too much for her fragile condition. Even something as simple as a moment of hearing a bird sing could lift her spirits for days. As ME is "invisible", she sometimes looked ok despite suffering immensely from severe flu-like exhaustion, body-wide muscle and joint pain, stiff neck, unstable blood pressure and heart rate, muscle twitches and spasms, chronic lightheadedness, sound/vibration sensitivity, nausea, food intolerances, and extreme thirst, among other symptoms.

She was often unable to speak, and only had a brief period on "good" days when she had the cognitive energy to focus, which she devoted to environmental advocacy as well as researching and planning her own path to recovery.

Eventually, her condition worsened to a state where she could no longer enjoy these tiny slivers of light that are so rare in severe ME.

Despite her suffering, Heather maintained solid hope for a full and active future and worked to spread awareness about this unimaginably debilitating, yet widely misunderstood and underfunded, neuroimmune disease.

Those with severe ME are largely rejected by the medical community, leaving extremely ill patients even more vulnerable. Those who are most in need of medical care and caregiving support often do not have it.

Despite her circumstances, she deeply appreciated the ordinary things in life that are so easy to take for granted. Ultimately, these moments were not enough to sustain her through the dark and challenging times of having severe ME.

Heather had a close-knit circle of friends and family who loved and advocated for her. It was with great sadness that she could not spend more time with her loved ones, especially her nephew. We have lost a beautiful soul and friend.

Please help honor **Heather**'s memory by being a tireless advocate for those who have severe ME and who have been rejected or forgotten by medicine. You have not been forgotten by the ME community. Never has there been more hope on the horizon.

Heather posted the following poem on her Facebook page a while back. Be free, star traveler. - with **Christina Steiger** (https://bit.ly/2QbkZQJ)

When I die,
my atoms come undone;
I will be space dust, once again.

The wind will carry me;
scatter me everywhere;
like dandelions in springtime.

I'll visit worlds and alien moons;
it will be so damn poetic –
until I land on your sandwich.

https://bit.ly/2Sg4o0K

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

The National Centre for Neuro-immunology and Emerging Disease, Australia

By **Professor Sonya Marshall-Gradisnik**, **Dr Helene Cabanas**, **Ms Natalie Eaton-Fitch**, **Dr Leighton Barnden** and **Professor Don Staines** and the **NCNED Team**, **Menzies Health Institute Queensland**, **Griffith University**, Australia.

Researchers from the National Centre for Neuroimmunology and Emerging Diseases (NCNED), Menzies Health Institute Queensland, Australia, have recently published significant world first research findings.

Researchers at the National Centre for ME/CFS in Australia have previously identified the faulty receptors, known as Transient Receptor Potential (TRP) ion channels, to be associated with the ME/CFS pathology. These specific receptors are involved in sensory reception, meaning they will detect any changes in external and internal environments (e.g. light, temperature, vibration, osmotic pressure, odours, chemicals, viruses, bacteria, stretch and torsion) and can be then related to many symptoms in ME/CFS. More particularly, TRPM3, a widely expressed receptor implicated in pain detection and inflammation, has been reported to be faulty and involved in the immune dysfunction, characteristic of ME/CFS.

In this new ground-breaking research, NCNED Researched have discovered the pharmacological drug known as Naltrexone significantly improves the function of the faulty TRPM3receptor in immune cells obtained from ME/CFS patients, using the gold standard experimental technique. This world-first discovery suggests an improvement of immune cell functions and therefore new potential pharmaco-therapeutic interventions for the benefit of ME/CFS patients.

Moreover, neuroimaging investigations conducted by NCNED Researchers have previously demonstrated the involvement of structural and functional neurological changes in ME/CFS patients. NCNED Researchers have now reported world first findings for brainstem connectivity is impaired in ME/CFS patients. Importantly these deficits can explain the dysfunctions reported inrespiratory and cardiovascular systems, as well as the impaired attention, memory, cognitive function, sleep quality and muscle tone, characteristic of ME/CFS.

Finally, NCNED researchers also endeavour to robustly evaluate the research literature (also known as systematic reviews) in ME/CFS to provide a complete, exhaustive summary of current evidence relevant to a research questionand inform researchers and patients.

NCNED has previously reported in a number of systematic reviews that there is currently no conclusive evidence that suggests cytokine and microbiome serve as unique biomarkers for development of ME/CFS. In contrast, the new systematic review performed by NCNED researchers reports impaired immune cell function is a reliable and appropriate cellular model found in ME/CFS patients. More specifically, Nature killer cells, a type of immune cells, is now defined as a possible representative of other tissue cellular or organ system dysfunction and therefore is a good vector for research and diagnostic approaches for ME/CFS.

In summary, these recent and very promising results from NCNED provide new insights in the pathomechanism of ME/CFS to help develop an accurate clinical diagnosis and to improve treatment and prognosis for ME/CFS patients. NCNED is now continuing its investigations to develop strategies for identification and management of ME/CFS, in order to improve the quality of life of individuals with this illness.

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

MRC/NIHR Workshop: The ME/CFS Biomedical Partnership – Genetics and Biomarkers

This announcement sets out the current situation regarding a major and very ambitious bioresource initiative that involves the ME Biobank and the CFS/ME Research Collaborative (CMRC): The ME/CFS Biomedical Partnership.

The ME Association plays a very active role in both the CMRC (where I represent the MEA on the CMRC Board) and the ME Biobank. I also chair the Biobank Steering Group.

The primary aims of the project are to discover genetic clues as to why some people might develop M.E. and to find biomarkers (abnormalities in the blood) that are relevant to diagnosis, causation and management. The existing work of the ME Biobank, in collecting and supplying blood samples for all aspects of biomedical research will be considerably expanded if the funding for this new project is granted.

It has already involved extensive consultation with the Medical Research Council (MRC), National Institute of Health Research (NIHR), and representatives of the ME patient community and if funded will continue to do so.

The forthcoming workshop, which will involve the key players – MRC, NIHR, independent researchers, members of the CMRC, the ME Biobank, and representatives from the ME patient community – is a very important step forward in the development of this work.

The application will be formally submitted to the Medical Research Council and National Institute of Health Research early in the New Year.

Over the last seven years, we have run five successful conferences, with a sixth planned for March 2020, fostered new collaborations and have established a series of working groups to drive forward specific areas such as medical education.

We have worked in collaboration with researchers, the patient advisory group, charities and mainstream funders throughout this time and are delighted to see that our collective effort has led to the ME/CFS Biomedical Partnership being established. This new team will now work together to submit an application for funding to drive forward this ambitious project.

Lead investigators for the Partnership are human genetics specialist and CMRC Deputy Chair, **Prof Chris Ponting**; and clinician **Dr Luis Nacul**, who leads the CureME team at the UK M.E./CFS Biobank.

Dr Luis Nacul says: "The CureME team at the London School of Hygiene & Tropical Medicine is excited to announce that it is collaborating with the CMRC, to submit a research proposal on M.E./CFS to the Medical Research Council and the National Institute for Health Research.

"The CureME team is a critical partner in this informed and competitive submission, and is focusing at this early stage on developing the research proposal and ensuring the accurate categorisation of people with ME/CFS, using diagnostic criteria harmonised with our own protocols and with the US Centers of Excellence for ME/CFS (NIH funded).

"We will also continue our own research within the London School of Hygiene & Tropical Medicine, supporting transparent, multidisciplinary research informed by and for the benefit of people with ME/CFS. We are confident that this collaboration will help to accelerate much-needed research in this field, enabling further biomedical studies into well-defined ME/CFS."

The UK CFS/ME Research Collaborative (CMRC) and the CureME research team – UK ME/CFS Biobank – at London School of Hygiene & Tropical Medicine (LSHTM) have collaboratively identified a research proposal that it is seeking to take forward to the Medical Research Council (MRC) and the National Institute for Health Research (NIHR).

To enable the researchers to develop a fully informed and competitive proposal, the MRC/NIHR is supporting a workshop to bring together scientists, charities and patients, to provide recommendations to improve the research proposal. Following this workshop, a research application will be submitted to MRC and NIHR for consideration for funding, following peer review.

Dr Charles Shepherd, Hon. Medical Adviser, ME Association

Source: https://bit.ly/2sNG5wk
Slightly shortened by the editors

Vital New Research could lay bare The Cause of One of World's Cruellest Illnesses

The ME Association announces three new research grants into an incurable disease that affects 250,000 Brits

The UK charity is proud to reveal it is funding three new projects to help solve the mysteries of myalgic encephalomyelitis – also known as chronic fatigue syndrome – and how it is treated.

The ME Association can announce a new tranche of funding totalling almost £200,000 through its Ramsay Research Fund https://bit.ly/34DcvXG. The charity – which relies solely on donations and membership fees – has already invested more than a million pounds in biomedical research. It considers quality research to be a key priority as it offers the best hope for better understanding, improved diagnosis and treatment.

Grant One: The UK ME/CFS Biobank (£99,766)

The world-leading ME/CFS Biobank (UKMEB) is the only one of its kind in the UK. Here, the analysis of blood samples could reveal crucial biomarkers to provide a deeper understanding of what causes ME, and how it could be accurately diagnosed and treated.

The project, led and managed by the Biobank team at the London School of Hygiene & Tropical Medicine, is funded through the ME Association's Ramsay Research Fund.

This new ME Association funding will sustain and allow the Biobank to expand over the next two years and ensure a steady supply of blood samples to ME researchers around the world.

Jack Butterworth, a Project Manager at the Biobank, said:

"Over the past two years we have released samples to six research institutions in the UK alone, and many more in Europe, South America, Asia and the USA. The new, two-year award will build on that success, enabling further releases and the replenishment of depleted samples.

The award will also enable further communications and fundraising projects, raising the Biobank's income and reducing its reliance on grant funding. The funding will also allow the team to continue to work to develop biobanks elsewhere in the world, using protocols that are harmonized with the UKMEB's. Exciting work is already underway in the USA, Canada and Australia."

Grant Two: **Dr Karl Morten** and the University of Oxford (£69,150)
The ME Association is delighted to announce it has granted vital funding to **Dr Karl Morten** https://bit.ly/2PKGhW5 and colleagues at the University of Oxford, who are investigating blood abnormalities in ME patients. The funding will enable scientists to continue examining a link between blood plasma abnormalities and dysfunctional mitochondrial energy production in ME patients. This grant will also help to bring in more Oxford researchers from various disciplines and create a Centre of Excellence for ME Research in Oxford.

Dr Karl Morten:
"We are extremely grateful to the ME Association for providing funding for our new 12-month project exploring the plasma factors in ME/CFS and their impact on mitochondrial function.

"This study will compare ME/CFS patients with patients diagnosed with other fatigue-inducing conditions to look at changes in mitochondrial dynamics."

Grant three: **Dr Keith Geraghty** and the University of Manchester (£25,000)
The third grant goes to **Dr Keith Geraghty** https://bit.ly/34P46Rb and colleagues at the University of Manchester, where it will be used to analyse what happens to ME patients in the crucial time between the onset of their symptoms and a diagnosis being made. It is the first-time research in this area has been commissioned on such a level.

Dr Keith Geraghty:
"ME is a disabling condition that greatly impacts the lives of sufferers. Many report problems getting an early diagnosis and appropriate medical care.

"We found almost no research on the 'diagnosis of ME/CFS', specifically how long it takes patients to get a diagnosis in the UK and the process patients go through to get a diagnosis.

"We want to explore this topic to better inform clinical practice and guidelines for treatment."

Source: https://bit.ly/2Mew1Dh

How Psychiatric Referrals Influence Stigmatization in Patients With ME and CFS

An examination of American and British models

From the Discussion

The present findings indicate that patients with ME and CFS who have been referred to psychiatrists are likely to perceive illness stigma and feel estranged from others due to their illness. As previous studies have shown a high propensity of patients with ME and CFS to be misdiagnosed with a psychiatric condition (**Deale** & **Wessely**, 2000), these referrals are likely a cause of anxiety and stigma for the patient receiving them.

The relationship between psychiatric referral and estrangement was mediated by perceived stigma, yet the impact was stronger for the British sample than the American sample. Despite the different mediation model outcomes due to the moderation effect of country, all three variables correlate with one another for individuals from both countries. These findings corroborate the qualitative accounts that have been reported in previous literature (**Åsbring** & **Närvänen**, 2002; **Dickson et al**., 2007; **Jason**, **Taylor**, **Plioplys**, **Stepanek**, & **Shlaes**, 2002), which suggest that physician attitudes related to stigma and estrangement of individuals with ME and CFS.

Findings indicated that patients are at risk for estrangement and high stigma. Stigma can impair help-seeking and predict mental health challenges (**Clement et al**., 2015; **McManimen et al**., 2018). Estrangement is also a risk factor for patients because socially isolated individuals may experience loneliness, and loneliness predicts subsequent depression (**Cacioppo**, **Hawkley**, & **Thisted**, 2010; **Matthews et al**., 2016). Thus, individuals with chronic illness who feel estranged may be at risk for depression (**Cacioppo et al**., 2010), as well as early mortality (**Smith**, **Jackson**, **Kobayashi**, & **Steptoe**, 2018).

The differences between the American and British models may, in part, be explained by different illness profiles and cultural differences. British individuals experience more severe symptomology than Americans across several indicators (**Zdunek et al**., 2015), which may impact their experiences with healthcare providers and peers. It is possible that a patient with more severe symptoms may be treated more negatively by physicians than someone with less severe symptoms, especially if the physician upholds a stigmatizing view of the illness. Another possibility may be due to differences in diagnostic and treatment guidelines between the two countries. In the United Kingdom, the National Institute for Health and Care Excellence (NICE) guidelines for ME and CFS stipulate the cognitive behavioural therapy (CBT) and graded exercise treatment (GET) should be part of the treatment program for patients with ME and CFS

While this has positive outcomes for patients with depression, patients report that GET often exacerbate symptoms and leaves them feeling more fatigued and more ill than before (**Wilshire et al**., 2018; **Maes** & **Twisk**, 2010). CBT has had more mixed findings, but it has been demonstrated that CBT's effectiveness is directly tied to patient comorbid diagnosis of depression (**Sunnquist** & **Jason**, 2018). While these guidelines are in place for U.K. practitioners, the Institute of Medicine in the U.S. does not have specific guidelines for treating ME or CFS. Attitudes toward the illness and treatment likely differ in Britain compared to America due to these nuanced sets of differences, as has been demonstrated with attitudes toward the cause of ME and CFS (**Zdunek et al**., 2015). These outcomes highlight the importance of co-production in patient healthcare, as stigmatization in patient healthcare can be reduced through the involvement of patients in planning and implementing their treatment and outcome options (**Turakhia** & **Combs**, 2017).

In summation, physician treatment, societal stigma, and the social estrangement of individuals with ME and CFS are interconnected in our two samples of patients. Findings indicate that referral to psychiatric treatment can be damaging when prescribed to someone as a means of dismissing physical complaints. Physicians can utilize a shared decision making treatment model to treat patients with ME and CFS (**Bieber et al**., 2008). This method involves mutual exchange of information between the doctor and patient, as the doctor holds medical knowledge and the patient holds knowledge about individual health experiences. This model has been effective for those with chronic invisible illnesses and may better allow physicians to aid patients who feel their symptoms are physical and not psychological (**Bieber et al**., 2008). By remaining sensitive, physicians, friends, and family can aim to improve the lives of those with ME and CFS.

http://siba-ese.unisalento.it/index.php/cpgp/article/view/20653

Submitted by **Prof.Leonard Jason**

Differentiating Post-Polio Syndrome From Myalgic Encephalomyelitis And Chronic Fatigue Syndrome

Lauren Klebek (https://bit.ly/2spe0eX), **Madison Sunnquist** (https://bit.ly/2PYQXAG) & **Leonard A. Jason** (https://bit.ly/2Sv9Z3f)
Received 24 Sep 2019, Accepted 28 Oct 2019, Published online: 06 Nov 2019

Abstract

Background: Overlapping and concomitant symptoms among similar chronic illnesses have created difficulties for diagnosis and further treatment. Three such chronically fatiguing illnesses, Post-polio syndrome (PPS), Myalgic Encephalomyelitis (ME) and chronic fatigue syndrome (CFS) fall under this category.

Purpose

The aim of this study is to examine and distinguish between core symptoms found in these illnesses (i.e. muscle pain/weakness, fatigue or exhaustion, and autonomic symptoms) via three methods of analysis (DePaul Symptom Questionnaire 2 (DSQ-2), Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36), and machine learning techniques).

Results

Items assessing onset and severity for individuals who reported having PPS were found to have experienced an onset of PPS related symptoms roughly 30 years after the onset of Polio. Items found in the DSQ-2, SF-36 compared all illness groups and found that participants with ME/CFS were more functionally impaired across symptoms than those with PPS. Across all analyses, three domains most commonly differentiated the illnesses (neurocognitive, Post-exertional malaise, and neuroendocrine).

Conclusion

Examining functional impairment amongst chronically fatiguing illnesses using multiple methods of analysis can be an important factor in distinguishing similar illnesses. These findings support further analysis of analogous symptomatology among other chronic illnesses to assist in diagnosis.

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

EV71 Infection Induces Neurodegeneration via Activating TLR7 Signaling and IL-6 Production

Zhen Luo, **Rui Su**, **Wenbiao Wang**, **Yicong Liang**, **Xiaofeng Zeng**, **Muhammad Adnan Shereen**, **Nadia Bashir**, **Qi Zhang**, **Ling Zhao**, **Kailang Wu**, **Yingle Liu**, **Jianguo Wu**
Published: November 15, 2019

Abstract

As a neurotropic virus, human Enterovirus 71 (EV71) infection causes hand-foot-and-mouth disease (HFMD) and may develop severe neurological disorders in infants.

Toll-like receptor 7 (TLR7) acts as an innate immune receptor and is also a death receptor in the central nervous system (CNS). However, the mechanisms underlying the regulation of TLR7-mediated brain pathogenesis upon EV71 infection remain largely elusive.

Here we reveal a novel mechanism by which EV71 infects astrocytes in the brain and induces neural pathogenesis via TLR7 and interleukin-6 (IL-6) in C57BL/6 mice and in human astroglioma U251 cells.

Upon EV71 infection, wild-type (WT) mice displayed more significant body weight loss, higher clinical scores, and lower survival rates as compared with TLR7-/- mice. In the cerebral cortex of EV71-infected mice, neurofilament integrity was disrupted, and inflammatory cell infiltration and neurodegeneration were induced in WT mice, whereas these were largely absent in TLR7-/- mice.

Similarly, IL-6 production, Caspase-3 cleavage, and cell apoptosis were significantly higher in EV71-infected WT mice as compared with TLR7-/- mice.

Moreover, EV71 preferentially infected and induced IL-6 in astrocytes of mice brain. In U251 cells, EV71-induced IL-6 production and cell apoptosis were suppressed by shRNA-mediated knockdown of TLR7 (shTLR7).

Moreover, in the cerebral cortex of EV71-infected mice, the blockade of IL-6 with anti-IL-6 antibody (IL-6-Ab) restored the body weight loss, attenuated clinical scores, improved survival rates, reduced the disruption of neurofilament integrity, decreased cell apoptotic induction, and lowered levels of Caspase-3 cleavage.

Similarly, in EV71-infected U251 cells, IL-6-Ab blocked EV71-induced IL-6 production and cell apoptosis in response to viral infection. Collectively, it's exhibited TLR7 upregulation, IL-6 induction and astrocytic cell apoptosis in EV71-infected human brain.

Taken together, we propose that EV71 infects astrocytes of the cerebral cortex in mice and human and triggers TLR7 signaling and IL-6 release, subsequently inducing neural pathogenesis in the brain.
Source: https://bit.ly/2t2ROY1

Submitted by **Allison May**

Proteomic and Metabolic Plasma iCPET Studies Funded

We have received an anonymous grant of $350,000 designated for the "Proteomic and Metabolomic Plasma iCPET Studies" within the OMF-funded Harvard ME/CFS Collaboration at the Harvard-Affiliated Hospitals. **Dr. David Systrom** and his colleagues at the Brigham and Women's Hospital have developed a valuable biorepository of blood samples from more than 300 people with ME/CFS – each with a well-documented patient history. In some of these patients, **Dr. Systrom** has identified a form of heart failure described as Preload Heart Failure (PLF), which presents in two forms: high-flow and low-flow.

Many of these patients suffer from dysautonomia as well as the diagnosis of Postural Orthostatic Tachycardia Syndrome (POTS), a syndrome that involves both the cardiopulmonary and the peripheral vascular systems. The dysregulations of these systems can cause: dizziness, fatigue, inability to exercise, lightheadedness, fainting, fast heart rate, nausea, anxiety, and blurred vision. The cause of the dysregulation is unknown, but it is likely that studying the interaction of these systems will lead to a clearer understanding of its origin.

The Harvard ME/CFS Collaboration's investigators will evaluate ME/CFS patient's blood samples that were extracted at three separate time-points: before exercise, at peak exercise, and one-hour after exercise. These studies will evaluate two separate blood compartments at these time points: the blood pumped from the heart and the blood returned to the heart. Therefore, six blood samples will be studied from each participant. Open Medicine Foundation (OMF) has raised funds for a cohort of the high-flow PLF ME/CFS patients to be compared to healthy volunteers.

Pulmonary artery hypertension (PAH) is one possible reason for unexplained fatigue and dyspnea, recent studies in the area of PAH offer a guideline for where to begin our in-depth analysis on ME/CFS. In these comparable studies, many differences were observed in the blood (proteins, peptides, phospho-proteins, and metabolites). These new findings in PAH are in areas of biology that are also of great interest to the ME/CFS research community. It is with hope that this newly funded study, performed specifically in the ME/CFS patient population, will lead to a better understanding of the underlying biology behind ME/CFS and PLF, while simultaneously identifying potential drug targets for future therapies. This recent funding will begin to enable extensive research and scientific exploration into this very important biorepository for these ME/CFS patients undergoing cardiopulmonary exercise testing. OMF is committed to continuing to raise funds to conduct these types of analyses on additional and similar ME/CFS patient groups using this invaluable resource at hand.
Learn more about the iCPET Study https://bit.ly/35g8CZ7.

Ronald G. Tompkins, MD, ScD
Source: https://bit.ly/2SUHkoF

Perturbation of Effector and Regulatory T Cell Subsets in ME/CFS

Perturbation of effector and regulatory T cell subsets in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Ece Karhan, **CourtneyL Gunter**, **Vida Ravanmehr**, **Meghan Horne**, **Lina Kozhaya**, **Stephanie Renzullo**, **Lindsey Placek**, **Joshy George**, **Peter N Robinson**, **Suzanne D Vernon**, **Lucinda Bateman**, **Derya Unutmaz**

doi: https://bit.ly/37xYLPW

This article is a preprint and has not been certified by peer review

Abstract

We hypothesized that immunological disruption is the major driver of this disease and analyzed a large cohort of ME/CFS patient or control blood samples for differences in T cell subset frequencies and functions.

We found that the ratio of CD4+ to CD8+ T cells and the proportion of CD8+ effector memory T cells were increased, whereas NK cells were reduced in ME/CFS patients younger than 50 years old compared to a healthy control group.

Remarkably, major differences were observed in Th1, Th2, Th17 and mucosal-associated invariant T (MAIT) T cell subset functions across all ages of patients compared to healthy subjects.

While CCR6+ Th17 cells in ME/CFS secreted less IL-17 compared to controls, their overall frequency was higher.

Similarly, MAIT cells from patients secreted lower IFNγ, GranzymeA and IL-17 upon activation.

Together, these findings suggest chronic stimulation of these T cell populations in ME/CFS patients.

In contrast, the frequency of regulatory T cells (Tregs), which control excessive immune activation, was higher in ME/CFS patients.

Finally, using a machine learning algorithm called random forest, we determined that the set of T cell parameters analyzed could identify more than 90% of the subjects in the ME/CFS cohort as patients (93% true positive rate or sensitivity).

In conclusion, these multiple and major perturbations or dysfunctions in T cell subsets in ME/CFS patients suggest potential chronic infections or microbiome dysbiosis.
These findings also have implications for development of ME/CFS specific immune biomarkers and reveal potential targets for novel therapeutic interventions.

Full text: https://bit.ly/2QFutUl

New Book From Dr. Byron Hyde, December 2019

Dr. Byron Hyde M.D. has released a short book on the relationship between M.E., Polio, Acute Flaccid Paralysis, and other Enteroviral-caused illnesses.

His evidence for this relationship is both medical and historical. It is also based on his more than 35 years of researching M.E. and dealing with M.E. patients, as well as other patients referred to him with a diagnosis of M.E. or "cfs", who turned out to have non-M.E. illnesses or pathologies.

The book is called "The Return of Polio to the USA" and is available through Amazon (softcover book) and Kindle (e-book).

This publication started out as a chapter in his upcoming book "Understanding Myalgic Encephalomyelitis". However it turned out longer than planned, and was published separately because of length, because of important statistics from the WHO, but mostly because of the urgency of the AFP crisis worldwide.

Enterovirus season starts in June in the Northern Hemispheres and Dr. Hyde calls for correct & prompt EV testing and sub-typing, in order to have proper statistics and research devoted to treatment and hopefully prevention of all EV-caused illnesses.

This is highly recommended reading for the general public, not just people with M.E..

Link to book:
https://amzn.to/2ZS61mX

The book "Understanding M.E." is now going through last-minute checking, and will be released soon.

Submitted by **Allison May**

ME/CFS-CCC Patients Exhibit Altered T Cell Metabolism and Cytokine Associations

Alexandra H. Mandarano, Jessica Maya, Ludovic Giloteaux, Daniel L. Peterson, Marco Maynard, C. Gunnar Gottschalk, Maureen R. Hanson

"It is clear that the immune system plays a role in ME/CFS.

Our data indicate that there are existing reductions in resting T cell metabolism in patients. In particular, CD8+ T cells have altered mitochondrial membrane potential and an impairment in their metabolic response to activation. Both CD4+ and CD8+ T cells have significant reductions in glycolysis.

This hypometabolism in T cells aligns with other findings of hypometabolism in ME/CFS cells.

Furthermore, ME/CFS patients appear to have altered relationships between plasma cytokine abundance and T cell metabolism, where proinflammatory cytokines unexpectedly correlate with hypometabolism.

Such a dysregulation may indicate that ME/CFS T cells have lost responsiveness to some proinflammatory cytokines.

Along with hypometabolism in immune cells, this is consistent with a possible ongoing infection, though such an agent has not yet been identified."

full text: https://bit.ly/2tmpVuj

Video about the study: https://bit.ly/2Fhhm6C

Dec 2019

Intra Brainstem Connectivity is Impaired in Chronic Fatigue Syndrome

Leighton N Barnden, **Zack Y Shan**, **Donald R Staines**, **Sonya Marshall-Gradisnik**, **Kevin Finegan**, **Timothy Ireland**, **Sandeep Bhuta**

Highlights

- RAS connectivity was detected in HC and CFS groups both during rest and task.
- Strong connections were active for CFS from hippocampus to midbrain and medulla.
- RAS connectivity was diminished in CFS in the brainstem and to the hippocampus.
- RAS nuclei generate oscillatory signals which facilitate thalamocortical signal coherence.
- Impaired RAS affects cortical coherence necessary for attention, memory and problem solving.

Abstract

In myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS), abnormal MRI correlations with symptom severity and autonomic measures have suggested impaired nerve signal conduction within the brainstem. Here we analyse fMRI correlations to directly test connectivity within and from the brainstem. Resting and task functional MRI (fMRI) were acquired for 45 ME/CFS (Fukuda criteria) and 27 healthy controls (HC). We selected limited brainstem reticular activation system (RAS) regions-of-interest (ROIs) based on previous structural MRI findings in a different ME/CFS cohort (bilateral rostral medulla and midbrain cuneiform nucleus), the dorsal Raphe nucleus, and two subcortical ROIs (hippocampus subiculum and thalamus intralaminar nucleus) reported to have rich brainstem connections.

When HC and ME/CFS were analysed separately, significant correlations were detected for both groups during both rest and task, with stronger correlations during task than rest. In ME/CFS, connections were absent between medulla and midbrain nuclei, although hippocampal connections with these nuclei were enhanced. When corresponding correlations from HC and ME/CFS were compared, ME/CFS connectivity deficits were detected within the brainstem between the medulla and cuneiform nucleus and between the brainstem and hippocampus and intralaminar thalamus, but only during task.

In CFS/ME, weaker connectivity between some RAS nuclei was associated with increased symptom severity. RAS neuron oscillatory signals facilitate coherence in thalamo-cortical oscillations. Brainstem RAS connectivity deficits can explain autonomic changes and diminish cortical oscillatory coherence which can impair attention, memory, cognitive function, sleep quality and muscle tone, all symptoms of ME/CFS.

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

New NCNED Publication

The NCNED team has just published a very important paper titled 'A systematic review of natural killer cells profile and cytotoxic function in myalgic encephalomyelitis/chronic fatigue syndrome'. Authors: **Natalie Eaton-Fitch**, **Stanley du Preez**, **Hélène Cabanas**, **Donald Staines** & **Sonya Marshall-Gradisnik** https://bit.ly/39CMQBU

NCNED is committed to publishing novel high quality and rigorous research papers in the field of ME/CFS. NCNED also endeavours to robustly evaluate the research literature (also known as systematic reviews) in ME/CFS to assist and inform researchers and patients.

NCNED has previously reported in a number of systematic reviews there is currently no conclusive evidence that suggests cytokines and microbiome serve as unique biomarkers for development of ME/CFS. Additionally, our reviews also reported that supplements do not sufficiently assist in the management of ME/CFS.

In Contrast, this recent systematic review by Eaton-Fitch and NCNED researchers now reports impaired NK cell function is the reliable and appropriate cellular model found in ME/CFS patients.

To view the article, please click on the following link: https://bit.ly/2MSIX22

Our research was based on a review of 523 publications of which 17 studies met rigorous scientific standards for analysis. Quality assessment was undertaken on study design, methodology and level of evidence.

NCNED is always thankful to every participant in our research.

We also would like to thank the Stafford Fox Medical Research Foundation, Mr Douglas Stutt, the Mason Foundation, the McCusker Charitable Foundation, Mr Adrian Flack, Mr and Mrs Ian and Talei Stewart, the Alison Hunter Memorial Foundation, the Buxton Foundation, the Henty Community, the Blake Beckett Foundation, Change for ME Charity, QLD ME/CFS/FM Support Association QLD Inc, the ACT ME/CFS Society and WA ME/CFS.

Best wishes

Sonya, **Don** and the NCNED team
November 26, 2019

News From the Open Medicine Foundation

Ron Davis's presentation at Columbia, November 25, 2019
https://bit.ly/37COZMt

Dr. Davis went to the Einstein Medical Center at Columbia University and gave a similar talk to 100 doctors and scientists in person and 184 more who logged in online. Again, they were surprised and shocked by the information he presented. He knew it was being Livestreamed so he didn't take questions, but talked for 1 1/2 hours and incorporated questions that he is commonly asked. Nobody left. **Ron** really emphasizes the prevalence and severity of ME/CFS, the need for medical care, the urgent need for research, the growing group of great scientists that are working on it and the fact that none of them have enough funding from NIH.

Chris Armstrong on Uninvisible, October 31, 2019
https://bit.ly/36l7g0t

OMF Science Liaison **Christopher Armstrong**, PhD, was the guest speaker on this episode of Uninvisible Podcast with host and chronic disease patient advocate, **Lauren Freedman**. The Uninvisible Podcast focuses on invisible conditions and invisible chronic illness.

In this interview, **Chris** shared that OMFCA is focused on research to establish the biology of ME/CFS, to bring treatments to patients and educate the medical community. **Chris** emphasized that patients are at the forefront of researchers' minds, focusing on getting treatments for patients as fast as possible while raising awareness to a broad audience. **Chris** also shared that the most significant change he sees in ME/CFS research in the last decade is the advances made by the Open Medicine Foundation.

Jonas Bergquist, Uppsala
https://bit.ly/36kZDaj

The newest OMF-funded ME/CFS Collaborative Research Center is at Uppsala University in Sweden. Led by **Jonas Bergquist**, MD, PhD, the Center is working in collaboration with the OMF-funded Collaborative Centers at Stanford University and Harvard-Affiliated Hospitals and is actively bringing in new European collaborators. The ME/CFS Collaborative Research Center at Uppsala University is focused on the targeted molecular diagnosis of ME/CFS with the goal of evidence-based strategies for interventions.

"*One can start to tie biology, chemistry, neurophysiology and neurochemistry to these symptoms, which is a very important and an important introductory step before a potential treatment and possibly a cure," said* ***Dr. Bergquist***.

Dr. Bergquist and his team are researching neuroinflammation through imaging and searching for biomarkers in the fluid that surrounds the brain and spinal cord (cerebrospinal fluid). The Uppsala ME/CFS Collaborative Research Center is currently working on the targeted analysis of hormone levels in ME/CFS patients to determine dysregulation, the measure of trace elements and metals in ME/CFS patients that may be relevant to the disease severity in individuals, and the development of technologies to create a mechanism for more patients to be able to provide blood samples to participate in research even remotely.

Working in collaboration with **Dr. Carmen Scheibenbogen** (Charité-Universitätsmedizin Berlin in Germany), **Dr. Bergquist** has found that 70% of ME/CFS patients show autoantibodies to beta-adrenergic and muscarinic receptors. **Dr. Bergquist**'s research is following up on these early findings to determine the mechanism behind the production of these autoantibodies.

Stanford

Symposium Videos Available:
https://bit.ly/2ZNNZ5l

The Third Annual Community Symposium on the Molecular Basis of ME/CFS, sponsored by OMF, took place on September 7, 2019 at Stanford University. It brought together hundreds of researchers, clinicians, patients, caregivers, families, and advocates, and thousands more by livestream. This link gives access to all the 18 video's of the presentations held.

Submitted by **Marilyn Simon-Gersuk**

Identification of Actin Network Proteins, Talin-1 and Filamin-A, in Circulating Extracellular Vesicles as Blood Biomarkers for Human ME/CFS

Akiko Eguchi, **Sanae Fukuda**, **Hirohiko Kuratsune**, **Junzo Nojime, Yasuhito Nakatomi**, **Yasuyoshi Watanabe**, **Ariel E.Feldstein**

Highlights

- Circulating EV number was increased in ME/CFS patients correlating to CRP and BAP.
- AUROC for circulating EVs was 0.802 allowing correct diagnosis in 90–94% of ME/CFS.
- Proteins in actin skeletal regulation and EB virus infection were identified in ME/CFS patients.
- Talin-1, filamin-A and 14-3-3 proteins were the most abundant proteins representing highly specific ME/CFS.

Abstract

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a serious, debilitating disorder with a wide spectrum of symptoms, including pain, depression, and neurocognitive deterioration. Over 17 million people around the world have ME/CFS, predominantly women with peak onset at 30–50 years. Given the wide spectrum of symptoms and unclear etiology, specific biomarkers for diagnosis and stratification of ME/CFS are lacking.

Here we show that actin network proteins in circulating extracellular vesicles (EVs) offer specific non-invasive biomarkers for ME/CFS. We found that circulating EVs were significantly increased in ME/CFS patients correlating to C-reactive protein, as well as biological antioxidant potential.

Area under the receiver operating characteristic curve for circulating EVs was 0.80, allowing correct diagnosis in 90–94% of ME/CFS cases.

From two independent proteomic analyses using circulating EVs from ME/CFS, healthy controls, idiopathic chronic fatigue, and depression, proteins identified from ME/CFS patients are involved in focal adhesion, actin skeletal regulation, PI3K-Akt signaling pathway, and Epstein-Barr virus infection.

In particular, talin-1, filamin-A, and 14-3-3 family proteins were the most abundant proteins, representing highly specific ME/CFS biomarkers.

Our results identified circulating EV number and EV-specific proteins as novel biomarkers for diagnosing ME/CFS, providing important information on the pathogenic mechanisms of ME/CFS.

Abbreviations

ME/CFS-myalgic encephalomyelitis/chronic fatigue syndrome
EVs-extracellular vesicles
CRP- C-reactive protein
BAP-biological antioxidant potential
d-Roms - diacron-reactive oxygen metabolites
AUC - area under the receiver operating characteristic curve
ICF - idiopathic chronic fatigue

Keywords

ME/CFS, Circulating EV, Non-invasive biomarkers, Actin network proteins

Source: ScienceDirect https://bit.ly/36odQ6a

9. Severe ME

Please Tell Me, I'd Like To Find Out

Please Tell Me, I'd Like To Find Out : The Invisibility Of The Carer

I have never been able to get even close to describing the full horror of our situation, the never-ending suffering, the overwhelming burden of neglect and misunderstanding, the almost total isolation.

When I take the dog out, or go cycling, I seem to enter a parallel universe, where I seem to be regarded, not quite a bachelor, but certainly not as my default state of "**Greg** and **Linda**".

So, some will ask me where I've been on the bike, I tell them the sea, 4 miles away. "It's a lovely day for it..." is their cheery response, as I wheel the bike around the back, not knowing just what agony my wife will be tormented with.

All the while trying desperately not to make the slightest noise that can plunge her into dangerous deterioration. Making sure, for example, that I unclip my bike helmet before entering the house and undoing the noisy velcro strips on my jacket.

What, I wonder, sometimes, would I say, if I was REALLY asked -" how are you?"

I wonder would I rage or cry, scream or go mad?

Who wouldn't, given the situation?

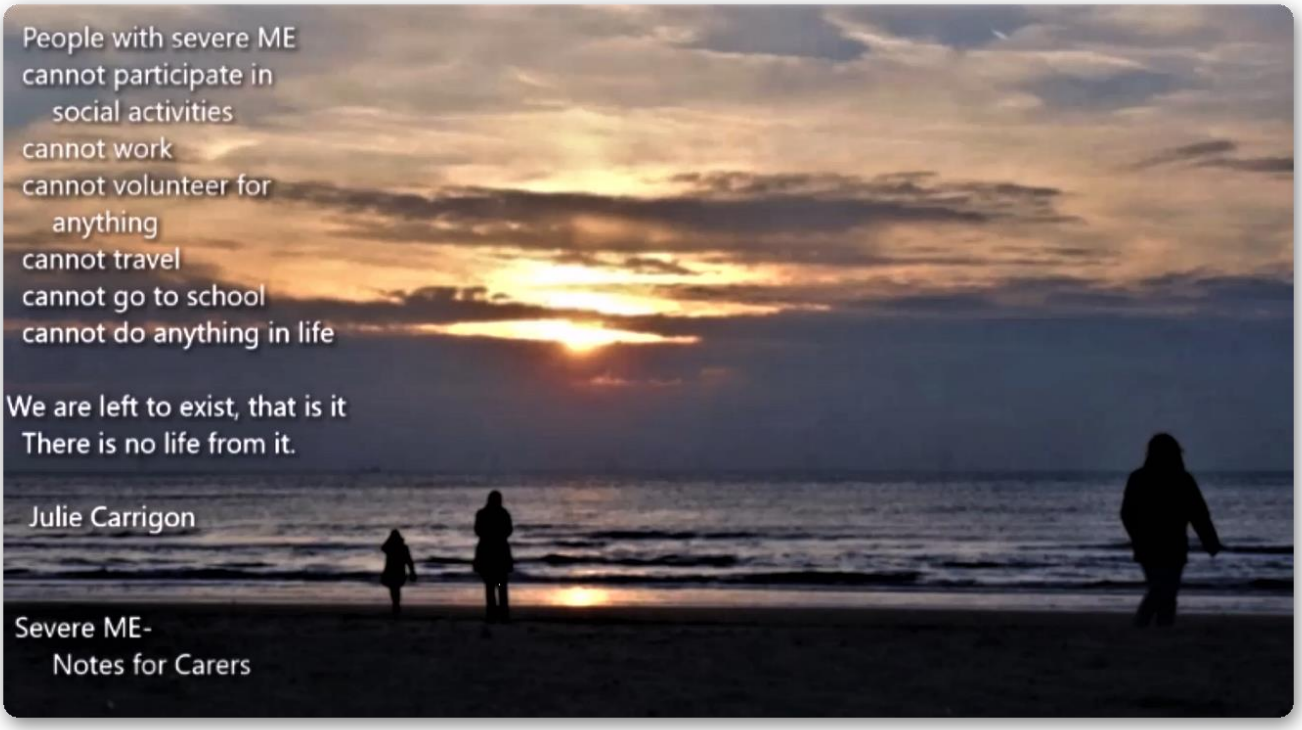
Instead, for the last 26 years, I just smile and ask the person how they are.

Paradoxically, on the deepest levels, I know extraordinary peace and experience daily, the deepest joy of our love and connection. It would be nice to share that too. We have amassed a lifetime of wisdom and insight into how how to grow and find meaning, even with everything taken away.

I have said it before, I thank God for my electric guitar and the gift of music. In this song I try to express all I have been saying above:
https://youtu.be/cw4H4MJJTCM

Greg Crowhurst, November 21, 2019

Source: Stonebird https://bit.ly/2EZDJNS


People with severe ME
cannot participate in
social activities
cannot work
cannot volunteer for
anything
cannot travel
cannot go to school
cannot do anything in life
We are left to exist, that is it
There is no life from it.
Julie Carrigon
Severe ME-
Notes for Carers

10. ME And Children

ME in Children And Young People – Part 3

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

The controversy in the UK

As already mentioned, there has been a major problem with the activities of the psychiatric school of thought. This has dominated research so that the search for a biological explanation for ME has been neglected. In particular, the psychiatrists have promoted the use of Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET).

More recently the research papers on which these therapies are based have been heavily criticised, and the US Institute of Medicine has withdrawn approval for both therapies.

The theory behind both therapies is that ME is not really a genuine illness but is due to a combination of "abnormal illness beliefs" (eg the illness is due to a virus) and deconditioning, hence the need for GET.

Suffice it to say, in my experience CBT just does not work (and is very annoying for the patient), and rigid forceful regimes of GET are positively harmful (eg increase activity levels by 10% per week even if it makes you feel worse). Currently these therapies are under review in the UK and hopefully will soon be consigned to the dustbin of history.

Case F

This 14 yr old girl had had probable ME since the age of 11 but her local paediatricians lacked the confidence to diagnose her. She was referred to a regional centre but was told she did not "tick enough boxes" to be given the diagnosis. Instead she was diagnosed as a case of "Idiopathic Chronic Pain Syndrome" for which a spell of inpatient physiotherapy was prescribed.

She received two sessions of vigorous physiotherapy daily, each lasting 90 minutes. At the end of 5 days she had deteriorated so much that, despite having been able to walk into the hospital, she was now bedridden and in much worse pain. Shortly afterwards she needed tube feeding

The problem of being a doctor confronted with ME, and the dangers of therapeutic enthusiasm

Example 3

A 14 yr old doctor's son developed ME and over the next 12 months was taken to all the supposed ME experts in the country. Someone asked him "What have you found out from seeing all these clever doctors?" and he replied "Not much, they don't understand it, but there is one thing I have noticed, it (ME) is a condition which induces an acute psychological disturbance in doctors confronted with it".

There is something unique about ME and its management in that a large number of "therapies" that help other conditions simply do not work in ME, and often make the patient worse.

Doctors are instinctively conditioned to try to make their patients better. In the case of ME it is better to start from a position of Therapeutic Nihilism (with the exception of Immunoglobulin and treatment for possible Lyme Disease)

Patients can understand and forgive the doctor's powerlessness, especially when the doctor remains involved and supportive.

The following case shows how the rigid application to a case of ME of a form of management from another area of medicine can have disastrous effects:

Case G

A 17 yr old girl had moderately severe ME, having suffered for over 5 years. Her paediatrician heard that she was sleeping 14 hrs a day and decided this was not a good thing. Her parents were persuaded to admit her to hospital for 4 weeks for "Sleep Hygeine". Under this regime she was woken at 8 am every day and limited to 8 hrs sleep per 24hrs.

She steadily deteriorated and at the end of the 4 weeks she was bedbound, in severe total body pain and needing tube feeding. The paediatrician justified her actions to the parents by stating "I have taken advice from the best sleep experts in the country" (Who clearly don't understand the sleep disturbance in ME)

Similar approaches are sometimes taken with postural hypotension, photophobia and hyperacusis, whereby patients are subjected to postural stress, bright light and noise in order to "desensitise" them. In my experience such approaches are invariably harmful.

Supportive Management

As already stated, once the doctor has coped with his/her feelings of helplessness, there is a great deal that can still be offered by way of support. These include:

- Remaining involved and seeing the patient regularly, rather than discharging the patient and saying "I'm sorry there is nothing I can do for you"
- Remaining open to new ideas eg possible Lyme Disease (which is of course treatable)
- Keeping an open mind regarding fresh diagnoses. ME does not protect from developing other conditions
- Providing written reports for employers, schools, insurance agencies, pension funds
- Protecting families of children with ME from disbelief and false accusations
- Giving appropriate advice re activity management
- Being willing to do home visits for cases that are too severe to come to your office
- Treating intercurrent illnesses appropriately

Of course all this is simply part of being a good doctor. However, in the UK I have witnessed many cases where every one of the above aspects of good supportive care have been lacking. Some severe bedbound patients have not seen a doctor in years.

Nomenclature

In general, patient groups much prefer the term "ME" to "Chronic Fatigue Syndrome" (CFS). This is because ME is a strong term with a clear implication of organic causation, whereas CFS is often used by professionals whose belief system is more towards the psychosomatic theory.

One advocate made the point that "Abolishing the term ME and replacing it with Chronic Fatigue Syndrome would be as unhelpful to the patient community as abolishing the term Alzheimer's Disease and replacing it with "Chronic Forgetfulness syndrome"

I would conclude by stressing that doctors who follow the above lines of support will find ME patients among the most grateful of all their patients

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Part 1 has been published in the June 2019 issue of the ME Global Chronicle, part 2 in the Autumn 2019 issue.

M.E. and School

We are very pleased to announce that **Professor Kristian Sommerfelt** has agreed to be the School Project's extended arm abroad.

The school project is a toolkit we have prepared in the form of a course on how to facilitate teaching for students with ME.

Thanks to fantastic efforts from volunteers in the counties of the ME Association, the course is now available throughout the country and during the year the course had close to 700 participants in total.

The feedback has been very positive and we hope and believe the work will help to make everyday life a little better for a group of children and young people in a very demanding situation.

Kristian Sommerfelt is also a member of the Steering Group for the School Project. He has long experience with ME and is a skilled communicator on the topic.

It will now be exciting to see if the School Project has opportunities to reach beyond the borders.

Prof. Kristian Sommersfelt, professor and child neurologist:

"*A project group of the Norwegian ME Association - Rogaland County Council has created a very useful toolbox for use in school for children and young people with ME.*

It consists of a lecture, some short, informative videos and a booklet. Overall, this provides both simple, clear and thorough, concrete information that will facilitate optimal social and educational participation for this extremely vulnerable patient group."

Source: Norges ME-forening - Rogaland fylkeslag https://bit.ly/39DZgcP

11. News from

Australia

Scientists can now apply for the $3m targeted funding for ME and CFS, Australian politicians are making sure it doesn't get wasted on CBT/GET again!
https://bit.ly/2tomuDb

Australia's federal government now has a $3 million grant round open, calling for research into ME and chronic fatigue syndrome. $3 million over three years is a huge increase on previous spending, yet is a tiny proportion of the $9 billion the government is spending on medical research over 10 years.

After two decades of Myalgic Encephalomyelitis and chronic fatigue syndrome research receiving less than $100,000 a year, Australia's federal government is now calling for funding applications to:

- Develop a scientifically valid, evidence-based understanding of the pathophysiology and aetiology of ME/CFS and the way it impacts on the physical, social and psychological wellbeing of affected persons.
- Identify approaches that will assist patients presenting with symptoms of ME/CFS to be accurately diagnosed, including the identification potential biomarkers to facilitate effective management and treatment.
- Cultivate interdisciplinary research collaboration, both locally and internationally.

Accurate diagnosis is a huge problem in Australia: less than one-third of people diagnosed with chronic fatigue syndrome and ME meet the International Consensus Criteria for ME. A quarter have exclusionary conditions which explain their symptoms and 15% have chronic fatigue but don't meet any of the criteria for chronic fatigue syndrome or ME. Anecdotally, others wait years or decades for a diagnosis.

No criteria specified for grant applications

No criteria is specified, which is concerning as **Prof Andrew Lloyd**, who has historically received the majority of government funding, describes 'ME/CFS' as sitting on a 'fatigue continuum' and does not use the Canadian or International Consensus Criteria for Myalgic Encephalomyelitis.

The request for research into 'psychological wellbeing' is concerning for a disease for which ineffective psychology treatments are currently prescribed in Australia's guidelines.

The grants were announced by **Health Minister Greg Hunt** earlier this year. Unfortunately, it is less than the $6 to $9 million the Minister had advised he would try and find in his meeting with ME Australia in November 2018.
Applications for funding will be open until 29 January 2020.

Senator Jordon Steele-John sought reassurance once again from the NHMRC that funding would not be spent on graded exercise therapy or cognitive behavioural therapy, mentioning the times he and previous Senator Scott Ludlam had raised this.

Senator Steele-John said these therapies are 'not only not useful but also quite damaging' and asked NHMRC CEO **Prof Anne Kelso** if this would be prevented.

"The focus of the targeted call for research is is on the pathophysiology of ME/CFS, in other words the underlying causes. The purpose is to focus on causes and diagnosis rather than possible treatments," Prof Kelso said.

Medical council agrees new guidelines are needed

National Health and Medical Research Council's Chief Executive Officer, **Prof.Kelso** has decided that the NHMRC should develop clinical guidance on ME/CFS. This is a major decision as the current guidelines were condemned by the Senate and organisations as soon as they were released back in 2002, saying they misrepresented the illness, made harmful management suggestions and had a bias towards a psychiatric-psychological approach to the illness.

"We also need to identify a funding source to develop the guidance," **Prof Kelso**'s response said.

The National Health and Medical Research Council (NHMRC) has not replaced the 2002 Australian chronic fatigue syndrome guidelines despite the fact the NHRMC's own regulations stated the guidelines were to be replaced after 10 years. In 2013 the NHMRC met with Emerge (then ME/CFS Australia (Victoria)) to discuss updating the Guidelines. They were due in 2014, according to information NHMRC published on its website.

Submitted by **Sasha Nimmo**

Belgium

Recent times have seen several governmental organizations, such as the Dutch Health Council (2018), the American Centers for Disease Control and Prevention (CDC) (2017) as well as the Canadian Alberta Health Services (2016) propose new guidelines for the cause, diagnosis and treatment of ME/CFS.

For children with ME/CFS, separate American guidelines have been published (Frontiers in Pediatrics 2017). The English National Institute for Health and Care Excellence (NICE) is also working on a new set of guidelines.

As per these guidelines, ME/CFS is being recognized as a serious chronic illness with a large impact on daily life. The causes of the condition, as well as whether it's a single condition or several illnesses described under the same moniker. The new guidelines do, however, state that it's not a "psychosomatic" but a "physical" affliction that can affect several body systems.

However, numerous questions - and also dissenting opinions - continue to persist, both regarding the potential causes of the illness as well as possible treatments. Several large-scale research projects in the near future might be able to shed some light on everything.

Cognitive behavioral therapy and gradual exercise therapy continue to remain the treatments of preference in our country. In fact, there's no clear-cut policy addressing ME/CFS at all here. And neither have our successively elected governments been able to accomplish anything in this regard.

Read more (Dutch):
https://www.gezondheid.be/index.cfm?fuseaction=art&art_id=26209

Check also these link:
http://www.12me.be/index.html

Eddy Keuninckx

Canada

To All ME Patients and Caregivers in Canada

Allies For ME is a new group working collaboratively to bring equity in research funding and access to appropriate medical care, treatment and support to the 580,000 Canadians living with Myalgic Encephalomyelitis (ME).

Please help educate our new MPs and Cabinet about ME by clicking on the link below and downloading a letter that you can personalize and send to your new MP.

Step-by-step instructions will help make it quick and easy for you.
http://bit.ly/2OCPAHq
Please email with any questions: coordinator@AlliesForME.ca

Source: Millions Missing Canada

Fibromyalgia and the Gut Microbiome

Scientists used to think that our DNA largely determined our health and development.

Then they came to realize that we all co-exist with microorganisms such as the bacteria in our gut or on our skin. The types and quantities of various bacteria could be a factor in health and development.

A recent study out of McGill University showed that people with FM had different proportions of various bacteria in their stool samples (more eloquently referred to as gut microbiota) compared to healthy controls. In fact, the researchers were able to diagnose FM correctly 88% of the time based solely on stool samples. [See Altered microbiome composition in individuals with fibromyalgia by Minerbi et al in the journal PAIN.]

Scientists at the University of Alberta (Edmonton) would like to replicate this study to see if they arrive at the same results. They would also like to take the study a step further – seeing if the difference in the microbiota could be causing symptoms.

What they would do is to take stool samples from people with FM and from health controls and inject them in mice. If the FM mice start showing certain behaviours like pain sensitivity or inflammation, this would suggest that the mix of bacteria could be responsible for FM symptoms. That in turn would suggest that rebalancing the gut bacteria could be a technique to treat FM.

The scientists are looking for $50,000 in funding for a feasibility study. Edmonton resident **Ivan Tolentino** is interested in fund-raising for this research study and has started an organization called The Fibromyalgia Research Project (FMRP) for this purpose. Along with his partner, **Briony**, they want to create greater awareness and better understanding about FM.

The National ME/FM Action Network has agreed that this research study is worth pursuing and will issue charitable tax receipts for donations to this research study. Donations can be made to the National ME/FM Action Network https://www.mefmaction.com and simply state FMRP or even just FM. Any donation made for FM will go specifically to this project. Any funds over this project will be reserved in this fund specifically for FM.

Source: QUEST, newsletter 121 – Winter 2019

Submitted by **Lydia Neilson**

Czech Republic

Creation of ME/CFS guidelines in the Czech Republic

The Czech Republic is lacking standardization of the medical care for ME/CFS patients. For people with this debilitating physical illness it has been really hard to get suitable medical care so far, although we have a solidarity based healthcare system and high quality medical care.

With the new Minister of Health, **Adam Vojtěch**, things changed for better. New Department of Patients' Rights Support was established on July 1, 2017 to improve communication between the Ministry of Health and patients.

Despite the fact that the Health Law guarantees to the Czech citizens free access to specialized healthcare services according to the latest knowledge and evidence based medical guidelines, ME/CFS sufferers had been falling through the medical and social system like patients in other countries.

In September 2018 patients with ME/CFS with the support of the patients' organization Club of patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (Club ME/CFS) sent an appeal to the Ministry of Health to change the situation for patients with ME/CFS. Department of Patients' Rights Support started to solve it.

On March 21, 2019 the first meeting organized by the Department of Patients' Rights Support took place. Representatives of employees of the Ministry of Health, Medical Associations and Club ME/CFS agreed to create ME/CFS diagnostic and treatment guidelines for general practitioners and to give a proposal to include ME/CFS into the Disabling Conditions Registry.

On the international ME/CFS Awareness Day on May 12, 2019, the Minister of Health Mgr. and Mgr. **Adam Vojtěch**, MHA, personally visited the Millions Missing action in Prague and met with the patients and representative of Club ME/CFS. He promised to support them and the guidelines creation process.

On May 31, 2019 a representative of Club ME/CFS attended the 14th International Research Conference IiMER in London, where he made contacts with ME/CFS specialists from the NIH and members of EMECC (European Myalgic Encephalomyelitis Clinician Council).

Consequently on June 19, 2019 Club ME/CFS sent a suggestion to the Ministry of Health to create a roundtable with international ME/CFS specialists regarding the Czech ME/CFS guidelines.

On July 4, 2019 the second meeting at the Ministry of Health took place and the outcomes were the necessity to find a Czech doctor who will cooperate with the international experts. Club ME/CFS representatives have been meeting doctors regarding this issue.

The Czech Republic has the Guarantee Committee which is responsible for national methodology of clinical guidelines developments. On July 15, 2019 Club ME/CFS sent the materials designed for the negotiations with the Guarantee Committee about adding ME/CFS guidelines to the planned clinical guidelines to the Ministry of Health. The next steps therefore will depend on the result of these negotiations.

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

Answer from Minister of Health **Magnus Heunicke** on question 246 on separating ME from functional disorders

Answer given by **Minister of Health Magnus Heunicke** (S) on December 16, 2019, on a question about separating ME from functional disorders posed by Peder Hvelplund (E): On November 18, 2019, the Danish Parliament's Health and Elderly Committee asked the following question No. 246 (General section) to the Minister of Health and Elderly, which is hereby answered.

The question was asked at the request of **Peder Hvelplund** (EL): "Will the Minister explain what initiatives are being taken in relation to the Parliamentary Resolution V82 (2018-19, 1st session) to separate ME and CFS from the list of functional disorders?"

Answer: In March 2019, in connection with inquiry debate No. F 28 on ME fatigue syndrome, the Parliament passed Resolution No V 82.

As a follow-up to the decision, the National Board of Health was asked to prepare a plan for how to best follow up on the decision text. The National Board of Health has also obtained information on the treatment of ME from Norway, Sweden and England.

The review of the treatment of ME in these countries shows that there are many of the same challenges in the three countries as in Denmark. A general lifting of knowledge about the disease is sought among health professionals, better and more uniform offers of investigation and treatment and more research into the causes of the disease and in effective treatment methods.

The review of treatment programs in Norway, Sweden and the UK also shows that, like in Denmark, cognitive behavioral therapy and graduated training are the most widely used treatments.

Based on the contribution of the National Board of Health and the experience of Norway, Sweden and the UK, there are some issues that require further discussion, including how we best ensure a specialized treatment of ME.

I look forward to discussing this with the rapporteurs at an upcoming rapporteur meeting.

With best regards
Magnus Heunicke / **Martin Zohar**
Patient Association receives award

The pension company PFA recently awarded their "heart cases" for 2020, and one of the selected ones is ME Foreningen, which is based at the Town Hall Square in Farum. "*For the past several years, the association has been helping to shout out the lack of care and treatment to this patient group to the health care system. In March 2019, the Folketing decided that the effort for the disease should be increased, but since nothing has really happened since then, the Minister of Health pulled in consultation on January 14. Then we have to see what happens*", says a news release.

The 5 regional centers for Functional Disorders, which are responsible for ME treatment in Denmark

In October 2018, the Interregional Working Group on Functional disorders that each of the 5 Danish regions must have a Center for Functional Disorders, which is located in the somatics: the regions' offerings for patients with functional disorders.

The Danish regions rely on this report, which contains the overall plans for the centers and the treatment of functional disorders, including ME. The plan is still in force, despite the Parliament's V82 decision to separate ME from functional disorders and to establish specialized ME treatment.

Hovedstaden Region

Center for Complex Symptoms, Social Medicine Unit, Frederiksberg Hospital. Officially opened 2019

Sjælland Region

Clinic for Liaison Psychiatry - Køge, under the Psychiatry Region of Sjælland, will probably be transformed into the Center for Functional Disorders at the beginning of 2020, during the somatics at the University Hospital of Sjælland.

South Denmark Region

Center for Functional Disorders, Pain Center, Odense University Hospital. Founded 2019.

Functional Disorders in the Children and Youth Department, H.C. Andersen Children's Hospital, University of Odense

Central Jutland Region

Department of Functional Disorders, Head-Heart Center, Aarhus University Hospital Founded 1999. Including Knowledge Center for Chronic Fatigue Syndrome, founded in 2012.

Northern Jutland Region

Center for Functional Disorders, Social Medicine Unit, Aalborg University Hospital, founded in 2019.

Source: **Millions Missing Denmark**

Finland

Millions Missing Finland wants to remind on International Human Rights Day, that Finnish ME patients, estimated at 10 to 50 thousand, are without proper illness recognition, treatment, support services and social security.

The Finnish Constitution states:
"The law guarantees everyone the right to a basic income during unemployment, sickness, invalidity and old age, and in the event of the birth of a child and the loss of a guardian." "Public authorities, as further specified by law, shall provide adequate social and health services for all and promote the health of the population. Public authorities shall also support the ability of the family and other persons responsible for the care of the child to ensure the well-being and individual growth of the child."

Millions Missing Finland calls for fundamental rights and equal treatment in the spirit of:

- Health care in Finland must comply with the WHO Classification of Diseases, in which ME (ICD10 G93.3) has been an independent illness in the category of neurological diseases since 1969.
- Health care in Finland has to comply with the definition of ME disease in the IOM 2015 report.
- Health care in Finland must begin to participate in international biomedical ME conferences and participate in international research efforts to address the disease.
- Symptomatic, individualized treatment should be provided to Finnish ME patients.
- KELA shall provide sickness benefits to ME patients as required by the Act on Occupational Pensions: "The medical report does not contain an essential description of the symptom supporting the diagnosis, since it may not be possible to draw conclusions from the description as to the effect on the retiree's ability to function." Presently KELA rejects ME patients' sickness allowance and disability pension claims, claiming that ME is a so-called "malfunctioning" that does not significantly affect the performance of daily tasks.
- Teachers need to be trained in the illness so that they can take into account the special needs of pediatric ME-patients and adapt their schooling to the condition of their illness.
- Child protection authorities need to be trained in ME to identify and understand the limitations and challenges of ME as they encounter children and their families.
- The urgent care and outplacement of ME pediatric patients must be stopped and decisions already made reversed. ME patients and their families must be supported in the tragedy they face, just as with other illnesses

Source: Millions Missing Finland

Germany

Charity concert "Rap for Good"

The charity concert "Rap for Good" took place in Berlin. It was sold out with 3000 guests and there was a livestream. The most popular German rap stars performed for free. Entrance fees and donations went to an ME patient and the Open Medicine Foundation. #MillionsMissing Germany was there with an info booth. All guests and viewers at the live stream were asked to tweet to the German Minister of Health and to demand research funds. The Hashtags #MECFS and #RapForGood were trending in Germany. There was a lot of press about the event and ME/CFS.
https://bit.ly/2S2afGK

First ME/CFS Forum in Hamburg

The German Association for ME/CFS organized its first symposium in Hamburg.There were about 130 participants – patients, relatives, doctors, scientists and representatives of patient organisations. The fully booked event was accredited as continued medical education (CME) for physicians.

- Facebookpost from the German Association: https://bit.ly/36HQFUb
- Website: https://bit.ly/2PVEe0b

Statement of the German federal government on ME/CFS

The Green Party has made an inquiry about ME/CFS to the German government. The response of the Federal Ministry of Health on behalf of the German government was shocking.

- The inquiry: https://bit.ly/2kniONS
- The answer: https://bit.ly/2kuqkXu
- Statement of the German Association for ME/CFS (plus links to all media reports): https://bit.ly/2mmCcLz

Short radio program on the dire situation of ME/CFS patients in Germany

(The following passage is copied from News in Brief on Science for ME)
A radio program on the public broadcast Bayerischer Rundfunk (BR) called "Wissenschaft und Technik" included a 5-minute report on the dire situation of ME/CFS patients in Germany. Science journalist **Yvonne Maier** mentioned the problems with exercise therapy and the controversial studies on which this treatment is based. **Maier** used the word "scandal" to describe the care of ME/CFS patients in Germany.
https://bit.ly/35vK92C (starts at 3:50)

Video "A hidden illness"

#MillionsMissing Germany has published a popular video about ME and the campaign #MillionsMissing. The video has German subtitles, an automatic English translation can be set on Youtube.
https://www.youtube.com/watch?v=qM-BTK80lk8

Article about severe ME

ze.tt (Zeitverlag) has published an article about ME. **Dennis** is 22, has been sick for two years and is very severely affected – he is completely bedridden, in need of care and can no longer speak.
https://bit.ly/2M294Df

German medical journal Ärzteblatt Sachsen

(The following passage is copied from News in Brief (https://bit.ly/34sdlGw) on Science for ME)

Dr. Carmen Scheibenbogen and colleagues have published an overview on ME/CFS. Translated into English the title reads "Chronic fatigue syndrome (CFS): Practical recommendations for diagnostics and therapy." The article includes a section on children and adolescents with ME/CFS and has been positively received on social media.
https://bit.ly/2EpXiyv

Submitted by **Joanne**

Ireland

The walls we continue to face

In short Myalgic Encephalomyelitis (ME) is not on the Waterford Disability Services approved list of disabilities. I was thus not eligible to get an assessment for Personal Assistant (PA) services. However I have a Primary Medical Cert, Mobility Allowance, a powered wheelchair from the HSE (our Irish Healthcare System), etc. etc. and my house is fully adapted for wheelchair use. After many emails, and a request from my Public Health Nurse, I did have 5 mornings of 45-minute home care. This was totally inadequate.

After I wrote my account of this senseless and challenging struggle to request to have autonomy over my care the Journal.ie online (https://bit.ly/36Ce5ua) newspaper (https://bit.ly/2sD4BA0) took on my story. Their edited version was scheduled to go out during the Christmas/New Year period. As it happened, I ended up in care the days after Christmas.

Taken into care

I had flagged various departments of the HSE to the fact that there simply was not going to be enough care over the holiday period. Although deemed eligible for weekend care, they kept telling me that there was no funding for this.

Both the article in the Journal and the blog post written by my ME Advocates Ireland colleague **Moira** about being in care (https://bit.ly/2YX9h04), gained a lot of attention on social media. They prompted the HSE into action and my care package was increased to twice one hour of daily care, seven days a week. After nearly two weeks in care I returned home.

Health in decline

My health had taken a big dip. Over the coming weeks my care package was increased to slightly longer hours in the morning. By February I was so ill that I had great difficulty speaking. It was as if the muscles in my face were unable to perform their basic function. I ended up in hospital with a suspected stroke. I remained there for three weeks. Unfortunately, one of the assessments I had to have was with a Functional Medicine Psychiatrist, as I was deemed 'sad'. It cannot be said enough that the biologically debilitating neurological illness ME cannot be successfully treated by functional medicine, and the call for an assessment by a functional medic could only mean that they believed my symptoms were all in my head.

The medical team must have seen vulnerability as a weakness, and brought me in to see the main psychiatrist. He had no interest in my account of having lived with this illness for two decades and being totally aware of what I am and am not capable of. He drew me a stick figure, a thought cloud and a bolt of lightning. (I am sorry I didn't ask for this masterpiece…). In a nutshell, I had to push through my limitations and have happy thoughts.

It has taken eight months to regain some level of well being again, but my health is precarious. There are many days I spend mainly inside my home, lying in my recliner chair, or confined to bed. There are days I can enjoy the peace of my garden and have my mind focused on creative pursuits. However, I am now rarely able to leave my home. Certainly not unaided. Which brings me back to the continued request for PA support from Disability Services.

No support to go outside of my home

As outlined a year ago, home care does not involve any care outside the home. My ongoing request for support to go to the shops, to the bank, to GP or chemist, or on a more social and wellbeing level, to go to the library, a café… continued to fall on deaf ears until a month ago. This is still very much a medical model of care. Someone who doesn't know me decides on what I can and cannot do.

In July I forwarded guidelines from the Department of Health regarding Disability Services. These were obtained through Parliamentary Questions on behalf of ME Advocates Ireland:

- "HSE Disability Services provide personal and social supports based on the needs of the individual, rather than the provision of services based on a specific diagnosis or condition
- The Government is committed to providing services and supports for people with disabilities which will empower them to live independent lives, provide greater independence in accessing the services they choose and enhance their ability to tailor the supports required to meet their needs and plan their lives."

Over the past year I have received many empty promises.

Disability Assessment at last, after 20 months of asking

In October a Disability Services Liaison Officer came to my house with my Public Health Nurse. We had a very frank, open, and considerate discussion. The many cracks I fall in because of ME not being recognized under disability were identified. She could clearly see how much my illness has impacted on my ability to function. And I should be able to go outside my door…

I truly felt heard. Believed. Understood.

I felt at last that my story is being circulated by someone within the disability services and not just via my emails, and via the limited assessment procedures available to the Public Health Nurse. I hoped I would finally be supported to leave my home. The assessment was a month ago.

I have not heard anything since, other than yet again a promise of a response, when I made an enquiry last week. No response to follow up email this week. My thoughts go from: "was this a ticking boxes exercise and thus fulfilled my request for an assessment". To: "they are taking their time to set up a proper care package, looking at all the identified cracks in the system…" Maybe, now the Personal Assistance Services Motion (https://bit.ly/2tiADBN) has passed in the Government on 19 November 2019, I will finally get an answer?

The perception that living with illness is a privilege

This year I had to totally re-evaluate who I am. I am an independently minded woman, but although living with this illness for 21 years, this past year has been one of big adjustments. I had to accept strangers into my private space. I had to accept getting help with basic personal care. I had to accept that I am yet again mostly housebound. I had to accept that I also need support to bring my creative ideas into being.

Some people suggest that I am lucky to have so much time for my creative life. That I am privileged to have my house adapted for wheelchair use, to take ownership of a powered wheelchair and have a loan of a HSE profiling bed (hospital bed). Maybe I feed this distorted image by sharing images of my creative pursuits? Even if these images only constitute a few minutes out of a day, or week? I rather share these visual snippets than the reality of pain, days in bed, at times loneliness. I tell my experiences through my puppets and other creative explorations.

I see myself as an advocate for people with ME and other chronic illnesses and disabilities. My quest for care and highlighting these struggles are not just for my own benefit. I hope to have a tiny say in the way people with ME in Ireland continue to hit brick walls.

I might not have the capability to convey politics surrounding ME, but I hope that with sharing snippets of my personal story and my visuals of my creativity I can make a small difference in the lives of my fellow 'hermits'.

Thank you for taking the time to read this.

Corina Duyn
Founder member of MEAI
Source: https://bit.ly/2Em5HTF

Norway

A Research Conference was held in Oslo on the 25th and 26th November, organized by the National Institute of Health, the National Competence Service and the Norwegian ME Association. One of the speakers was **Joseph Breen** from NIH.

Joseph Breen, who heads the Immunoregulation Section at NIH, stood in the auditorium in Oslo to tell how things are going. Fortunately, there was a lot of good he had to report, and a few things that were somewhat less good.

One of the most exciting is the extremely profound study they have initiated within the NIH itself. Here, some of the world's foremost scientists are working with the very best of technology, and not all diseases are prevalent in getting this type of study underway.

The number of patients in the study is not that great, but the examinations they do are unusually thorough and sophisticated. They should have 40 ME patients, 40 healthy controls and 20 with post-Lyme disease without fatigue. All ME patients have triggered ME after an infection. They have this requirement to try to get as homogeneous a group of patients as possible, so that they have a greater chance of finding something.

The patients come to NIH and are there for two weeks. It is a very comprehensive visit. It's pretty intense, to say the least, **Breen** said.

Some of the research that is done is demanding, expensive and depends on sophisticated technology - so there are not so many places in the world to do this kind of study.

Some of the patients will spend an extended period of time in a metabolic chamber, an advanced room where researchers can investigate a number of things related to how the body uses energy - a central theme in ME research.

What is the starting point for NIH researchers? Their overall hypothesis is that post-infectious ME is triggered by a viral disease that causes the immune system to create a brain dysfunction.

The arduous process of selecting patients and conducting examinations repeatedly (patients going into two rounds), makes the study take time. They have now had 26 ME patients in the first two weeks of examinations, while six of them have also completed the second round. **Breen** pointed out that the ME patients participating are making a heroic effort that has impressed him.

Breen said that their work to try to accelerate ME research started in earnest in 2016. " The quickest way to give more support was to donate more money to those ME researchers who already had studies going with funding from us," **Breen** said. In addition, they managed to get some experts involved who have not previously been involved in ME research.
Among them, **Mark Davis**, a world-leading immunologist.

Then they started a plan to get three ME research centers up and running in no time. Three leading research institutions have received around $ 32,5 million over five years as a start."We had to start more collaboration and a larger group of patients to research. All the research centers will publish the first results in a fairly short time. The researchers are finding discrepancies in the patients, and they're starting to report them," **Breen** said.

Ian Lipkin's group at Columbia University should have found a disorder in a body's metabolic process in some patients.

Derya Unutmaz group at Jackson Laboratory has found abnormalities in specific subgroups of T cells (a type of immune cell) in ME patients. There is also the study for evaluation in a scientific journal, which in experience takes some time.

Maureen Hanson's group at Cornell University has found disorders in the metabolism of T cells and has investigated a relationship between this and cytokines (signaling molecules in the immune system).

So several independent groups have now reported abnormalities in T cells in ME patients.

About the collaboration between the researchers **Breen** told: "It was a little heavy at first, because none of them knew each other before. But we have earmarked money they have to spend on collaboration, so it helps, he said with a smile." A strong investment in ME research has also been initiated in Canada." And we work with them to get synergy effects from this," **Breen** said.

He also mentioned that just over a year ago, NIH initiated a one-year process of gathering input from a diverse group of researchers, doctors, patients and patient organizations.

They should provide input into what gaps NIH can help close. We received that report in September, **Breen** said.

Their recommendations were:

- put in place a strategic plan for the research.
- get an internal group within NIH to promote cross-border collaboration.
- take steps to encourage more researchers to seek funding for ME research.
- Get more researchers into the field and reduce the stigma associated with the disease.

They are now working on this to follow up.

Source: **Jørgen Jelstad** on his blog «De bortgjemte» (the Hidden)
https://tinyurl.com/wuckfds

Submitted by **Ellen Piro**

Slightly edited by MEGC

New Zealand

The past few months have seen quite an upsurge in interest from GPs and GP education here in New Zealand. There has been work to produce some educational links (as below), and these have been popularly received, particularly as doctors can obtain CME points for some of these modules.

Goodfellow management 5.12.19 https://bit.ly/2My3fO9

Health Navigator 1.11.19 https://bit.ly/2QohLcz

Pathways 6.6.19 https://bit.ly/2MvlzYb

We also have links with Emerge in Australia, who also have access to another excellent GP training module

Angus McKay, a researcher who has worked with Professor Warren Tate at Otago University has had a paper published in the NZ Journal of Primary Health Care.

A neuro-inflammatory model can explain the onset, symptoms and flare-ups of myalgic encephalomyelitis/chronic fatigue syndrome
http://www.publish.csiro.au/HC/HC19041

I have also been invited to write a guest editorial on CFS for the next edition of this journal, which goes to all GPs in NZ

ANZMES – our national ME organisation continues to liaise with government regarding awareness and management of the illness, and it is planned to have a meeting with the Minister of Health (who is very supportive) in 2020.

Submitted by **Rosamund Vallings**,
Auckland NZ

Portugal

Over 40,000 people live with M.E in 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 1, part 2 & 3 to be published in the ME Global Chronicle op March and June 2020 respectively.

How did you get ill?

Elle - I didn't have a very obvious trigger, and I think it was a combination of things. The year I got ill, I had the flu followed by a bad virus. I was flying once a week for work, had also taken up road biking. I think that it's possible a combo of viruses and road biking damaged the ligaments and structure of my craniocervical junction in my neck, as I also now have a CCI/AAI diagnosis. Perhaps this is the root of my ME. It is my latest area of focus, but it's not something I'm able to pursue in Portugal as it is very specialized, except being able to get an MRI.

André - That's somewhat a difficult question, because it is one that still puzzles me. Usually, CFS patients report developing it after a viral infection but, in my case, it manifested itself following a stressful event at work. I had to make a tremendous effort to supress such stress at the spot, my body turned as rigid as stone and, when I got home, I took an anxiolytic.

It was a Friday, Monday was an holiday and both my stress subsided and my body relaxed but, from then on, "classical" symptoms of CFS appeared: insomnia, headaches (from a type which I never had), tremendous fatigue and post exercise malaise. This was in the beginning of November 2010.

Ana - I can't say for certain because my onset wasn't immediate, but I know when it started. In Christmas 2013 I managed to catch three infections in three weeks: herpes, an unidentified throat infection that might have been mono and the flu. Ended up being prescribed some antibiotics that probably made everything worse, but I eventually recovered from the infections.

However, as 2014 started, I wasn't feeling well and it didn't go away. I ended up getting diagnosed with major depression in April and started taking antidepressants, which was probably another mistake. I had atypical reactions to them and got much, much sicker as time went on.

Has it been difficult to get diagnosed?

Elle - I didn't get diagnosed in Portugal as I was living elsewhere. It took a year, although I think some doctors mentioned "chronic fatigue syndrome" and I ignored them. It took me a while to pay attention to that as a diagnosis as I thought it sounded like not a serious disease. And I knew I was very ill.

André - Tremendously. First, because I suffer from chronic depression and all the symptoms were dismissed as just a depressive episode, even though my body "knew" that the fatigue and the aches were different from those of depression; second, because CFS was (and still is) barely heard of and doctors did little more than giving me mainstream medication for the symptoms. I had to be the one making all the research (until I eventually found out that my symptoms were consistent with something called "Chronic Fatigue Syndrome"), bringing awareness to the doctors and fighting for alternatives, from trying specific bloodtests or exams to different medication. I was eventually diagnosed officially in 2012.

Ana - Yes and no. I was lucky. I felt at the time that the depression was probably a misdiagnosis, but I found no other answers it for two years. Just when I was feeling desperate and quit my antidepressants because I knew they brought me no benefit, someone suggested me a second opinion in psychiatry, this time at a private hospital. And since I had nothing to lose but money, I went for it.

This doctor told me right away that I wasn't depressed, but it was possible that I had ME/CFS. It took me around 6 months from that day to the diagnosis, after all the exclusions. I probably would have never been diagnosed with ME/CFS if I didn't find a doctor who knew of it. And I definitely would have never been diagnosed with it if I didn't have the means to pay for care at a private hospital.

That's why I feel fortunate, even after being misdiagnosed with major depression for two years. I often wonder how many other portuguese are also ill, but without the means to get a correct diagnosis.

- How does this disease affect you?

Elle - It has stopped my life essentially for 6 years. I am housebound and spend 90 to 100% of my day in bed. I need a lot of help from my family member who takes care of me. I can't cook, or help with housework, or drive. I can't work anymore and rarely see friends. It is very isolating, and tedious. It often feels like endless suffering.

André - Well, I am functional, that is, I work a full time job - with great difficulty (going through the day is a chore and I often have to be on sick leaves for a few days), I have a few hobbies (again, carried with great difficulty) and I can do some minor chores, though things like house chores and cooking are too much of a toll (if we take me working in account).

However, to put it simply and using an example I once read: if you divide life into work/duties, leisure and rest, then I have to cut one out. Thus, since the latter is mandatory, my life (and for my own mental sake) is an incredible and harrowing attempt to balance the former two, where caffeine and opioids (codeine, to be more specific) play a major role (and I make a point to mention the opioids given the problem the US face with addiction and, therefore, what desperate measures one has to take to live the semblance of a "normal" life).

Ana - I believe I must be moderately affected, being mostly housebound. I can leave home a couple times a week for short trips, but they usually leave me wasted, too tired to do anything other than rest. If I'm not careful and overdo it even more, I'll have to spend the day stuck in bed and deal with extra fatigue for weeks, if not months. I left my job in 2017 and became financially dependent on my partner since then. The constant effort of working full time was making me progressively worse to the point that I spent all time in bed.

One of my biggest hobbies was PC gaming, a relatively low impact one at that, and I had to abandon it because I didn't had the energy to stay seated at a desk and use a mouse and keyboard. I wasn't even feeding myself properly because I had no energy to eat. And my work productivity plummeted to the point that I was useless at the workplace. I couldn't read a paragraph and be able to make sense of it, or remember what task I did the day before.

I got better since I left work as I'm now able to pace, but every day is a balancing act. Do I make dinner or do I take a shower? Can this chore wait, even if it not being done negatively affects me in other ways? Sometimes I chose poorly and have to deal with the aftermath for weeks. Thankfully, I have a supporting partner. He understands that I do what I can, and sometimes even more than I should. I don't know where I would be without him.

Mike Harley

Romania

Based upon other European ratios, there are as many as 80,000 people living in Romania with M.E.

In an interview before running the marathon of Bucharest on October 13, 2019 **Mike Harley** spoke to the sister of **Andreea** from Iași who told him about her battle with M.E.

- How did **Andreea** get ill?

We really don't know that because the onset of the disease was when she was a student and it was very progressive. At that moment we saw a lot of doctors - none of them had any idea about ME/CFS. They always suggested she was depressed. She wasn't tested for viral infectuous or anything else. She didn't have fever or something viral in her youth.

- Has it been difficult for her to get diagnosed?

It took like more than 10 years. She wasn't diagnosed in Romania- she saw here lots of doctors - none of them thought about ME - only depression. She even had treatment for depression without any result. She moved with her husband in Sweden where it took 6 years to get her diagnosed. They had the same problems there - no one believed her.. until I wrote a letter to her doctor describing ME. After that he sent her to ME clinic in Stockholm - Bragee Clinic where it took another six months to be diagnosed.

- How does this disease affect her?

Extremely severely - she is bedridden, isolated, in complete darkness, and silence, with trouble eating.

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

We haven't found any association. If one exists then they're not on the internet. If you find out something about such an association please let me know- we are desperate at the moment, seeking help.

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

We saw four neurologists up until now- all professors in different cities in Romania, one cardiologist, an infectious specialist etc - none of them do anything for ME, just saying they haven't heard of ME and they don't believe in it. The government has nothing to say to us, we are just ignored.

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

There is no adequate support for us. They cannot receive benefits with this diagnosis, you have to have something else. At least this is our story.

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

Well there is no adequate treatment - we were told just to continue the treatment we received in Sweden. Other doctors we saw were very skeptical about our treatment. I would like to see more open minded doctors - not just to tell us I never heard about that so you better go somewhere else. Also I would like there to be a clinic for complex diseases where we could go for an advice. Most importantly I would like if there would actually be some sort of treatment.

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

At the moment I cannot be positive at all - she is too sick, is without treatment and just left alone by the state.

Mike Harley

Scotland

Chronic fatigue syndrome sufferer considered euthanasia after lack of help from NHS

ME (myalgic encephalomyelitis) sufferer **Eileen Munro** believes not enough is being done to help people like her, whose lives have been devastated by ME (myalgic encephalomyelitis). She is demanding NHS Scotland provides services fit to cope with the 21,000 people who have the much-misunderstood condition. **Eileen**, 56, from Edinburgh, has suffered constant fatigue and often intense pain for more than two decades and says she has had little support from NHS Scotland. She believes that with so many people affected, Scotland needs a centre of excellence to tackle the symptoms and improve the lives of sufferers.In Scotland, there is one nurse-led clinic, based in Fife.

Eileen, the author of two best-selling memoirs, said: "They do their best but don't have the expertise or the resources to make a difference and they're not accessible to ME patients in distant parts of Scotland. Given the number of people whose lives are ruined by this condition, you'd think there would be greater urgency to provide support and that the NHS would fund research and effective treatment. I just want the right to be able to access safe housing, medical support and security without having to live under a stress cloud all my life." **Eileen** was left with ME after a brain infection, viral encephalitis, which resulted from a severe attack of chicken pox more than 20 years ago. She was hospitalised with collapsed lungs and swelling on the brain, and has never fully recovered. During one prolonged period of extreme pain that led to her being hospitalised for a week earlier this year, **Eileen** found herself googling the Dignitas Clinic in Switzerland as she was considering ending her life there. She said: *"I feel ashamed of that."*

Many ME sufferers in the UK have had cuts to their benefits – despite 250,000 people being diagnosed with the neuro immune condition. Several medics believe it is a psychological condition, often driving sufferers to despair. A Welsh councillor recently committed suicide after diagnosis. Sufferers have been offered a ray of hope by Scotland's chief medical officer, **Dr Catherine Calderwood**.

At a recent meeting of the public petitions committee at Holyrood, she pledged to ask experts to analyse trials. A Scottish Government spokesperson said: "*We support the development of new and effective approaches to diagnosis and treatment.*" Earlier this month, the Scottish Government published a five-year action plan to support people with a neurological condition backed by £4.5million of funding. "The plan, developed with the neurological community, will ensure people get access to personalised care and support, regardless of their particular condition or where in Scotland they live."

Source: Daily Record https://bit.ly/2QxV3yA
With thanks to Lochaber PVFS/CFS/M.E. Support Network
https://bit.ly/2QHUItt

Sweden

Petition

In Sweden at the start of October a petition has been started to ask officials and politicians of the regions of Sweden and the government if people with Me aren't worth taking care of: https://bit.ly/35nih04

The ME protest action was started due to the fact that the work to provide specialist care for Myalgic Encephalomyelitis (ME) in the Västerbotten region has stopped, despite a political decision on this already in 2018. Since there is no specialist reception for ME north of Stockholm and the vast majority of the sick cannot make long journeys without risk of getting worse, it is of utmost importance to try to get officials and politicians in the Region of Västerbotten to understand why it is not possible to further delay the work of building a center for ME-care.

But the question of the unequal and, in principle, non-existent care for people with ME is greater than that and applies not only to Region Västerbotten but to the whole of Sweden. Therefore, the patients demand that the government and parliament ensure that all regions prioritize good and adequate care for people with ME too.

"The protest campaign # ME care is our way of saying: It is enough now! We can't wait any longer! Because even though we are chronically ill, the situation is extremely acute. ME is a debilitating disease and people do not get the support they need at all. Care is not equal to us. Not good and adequate. Not patient safe. And the care offered to us is absolutely out of proportion to the need!"

Sign if you also think that the care situation for people with ME is unreasonable!

Why is this important?

It is estimated that there are approximately 40,000 people with the neurological disease ME in Sweden. It affects people of all ages and often starts after an infection. Everyday life is severely limited by a variety of severe symptoms from the entire body. The mildest patients have an activity impairment that is reduced by half and the most severely ill are bedridden around the clock.

A major symptom of ME is exacerbation of exertion. Research has shown that the cells' energy production no longer functions properly and that the body therefore does not recover after effort. This produces extreme reactions where ME symptoms are also increased by things that are not at all strenuous for a healthy person. The deterioration may be delayed, but will remain for more than 24 hours. It can also become permanent.

Unfortunately, there is no cure for ME yet, but care needs to be focused on trying to relieve symptoms and increase the quality of life without triggering deterioration.

There are extremely few healthcare providers who investigate and treat the diagnosis in relation to the need. The number of specialist clinics in Sweden can be counted on one hand and none of these are located north of Stockholm.

Today, only about 10% of people with ME are estimated to have an established diagnosis. Knowledge in other care is low. Prejudice and distrust of the diagnosis make it even more difficult for people with ME to get the help and support they need. For example, there are regions that consistently deny people with ME referral for ME care in another county.

However, outpatient care is not a good solution for everyone, as it is in principle impossible to implement without deterioration for a very large proportion of ME patients. For those with a more severe degree of the disease, home care is just as difficult. Yet many home visits are denied.

Thus, people with ME are not only at risk of receiving improper and inadequate care that worsens the disease, but many simply become without care.

For example, in the north, not only specialist care is lacking, but many have no care since neither care centers nor neurologist clinics want to take care of us. At the same time, a large part of the problems coming with ME have compensation from the Swedish Social Insurance Agency and other support, such as home care and assistance, which makes a functioning care contact extra important. Due to the nature of the disease, it is crucial that there is adequate biomedical specialist care available to people with ME in every region of Sweden and that this care makes home visits to those at risk of getting worse from leaving home.

Website for #ME Care Services: https://mevardsaknas.wordpress.com

Source: Millions Missing Sweden

Switserland

Recently in Switzerland there was some publicity on ME/CFS, both in the French and in the German-speaking part.

When fatigue becomes chronic
Chronic Fatigue Syndrome: a name that sounds not too scary. That's wrong. Exhausted, the patients have pain everywhere, as if they had a permanent flu. **Caroline, Nella** and **Protazy** tell about their daily lives.

Documentary broadcast by RTS: A report by **Sabine Pirolt** and **Vanessa Bapst** (in French, about 24 minutes long)

Dizziness, nausea, pain, headache, feeling of suffocation ... so much suffering linked to chronic fatigue syndrome ... Many people are unaware of the existence of this disease recognized by the WHO. This fatigue, which has nothing to do with what we know, affects more than 20,000 people in Switzerland. It seriously alters their daily lives, as evidenced by witnesses to this program. Currently, researchers do not have a single molecule to oppose the disease. Is a track looming?

Source: 36.9° https://bit.ly/2FiMAdv

A long article written by **Isabel Brun** about Swiss patients **Anna**, **Jonas** and **Dania** has been published in Tsüri, a magazine in German. **Jonas** recently established the Swiss ME-association (SGME) together with **Maya Leutwiler**.

An 'appetizer':
The disease that nobody knows
Chronic physical illnesses are often dismissed as mental illnesses in Switzerland. One of these is myalgic encephalomyelitis, which is also popularly known as chronic fatigue syndrome. The disease involves more than what society understands by chronic fatigue.

Anna is lying in her bed. She pulled the blanket up to her chest, her hair is tied in a bun, three rings adorn her hand. Dog **Kafka** is lying on her lap, curled up into a ball. At first glance, **Anna** does not appear to be seriously ill. And yet she is already more than half of her life. Since she was 16, the 33-year-old has been struggling with a number of symptoms - triggered by a multi-system disease called myalgic encephalomyelitis, in short M.E., or Chronic Fatique Syndrome (CFS).

"I was a very ambitious person," says the young woman. It was but natural for her as well as for those around her that they would go to high school, complete a course or study and contest a professionally successful future. But it wasn't to be like that…

In her teenage years, **Anna** fell ill with Pfeiffer's glandular fever and never fully recovered from it.

Not resting enough is the biggest mistake that can be made in the initial phase of the disease, says **Dr. Protazy Rejmer**. The medical advisor of the ME/CFS Association Switzerland fell ill with ME/CFS himself in his young adulthood and because of this fate decided to study human medicine. He is advocating for more research in the field already since many years.

While **Rejmer** is only mildly affected, **Anna**'s disease increasingly developed into a moderately severe stage during puberty. That is typical, explains the doctor: "In contrast to depression, ME/CFS worsens the condition of sick people due to physical exertion." An important piece of information that **Anna**, like many other people affected, was denied at the time of her illness.

Only much later, when **Anna** is already in her early twenties and her symptoms - a condition like the combination of flu and hangover - can hardly be endured, does she seek help from a psychiatrist. He immediately recognizes that her suffering is not psychological in nature - "an exception," as she says today. Awareness of the existence of ME/CFS has increased in recent years, but there are still doctors who do not know the disease or misinterpret the symptoms and would dismiss it as depression, confirms **Rejmer**.

Source: **Tsüri** https://bit.ly/2SWvtWO

Links submitted by **Maya Leutwiler**

The Netherlands

Implementation Dutch Citizens Initiative
For an update and news about the implementation of this utterly successful Initiative, which has been running since 2011, see"Dutch Citizen Initiative". It is entering a new and crucial phase.

#GivingTuesdayNL
The Dutch ME/CFS association asked members and other people to make a donation for Giving Tuesday, with the purpose of spreading a physical copy of the Dutch translation of the International Consensus Primer for Medical Practitioners (ICP) to general practitioners. The costs were €6,- per copy, and on 31 December, which was the last day of the promotion, €1478,- had been donated. This is enough to send around 246 copies of the ICP.

The initial goal was to gather €1500,- as this would allow the costs to be split in half, allowing for 500 instead of 250 copies to be sent around. At the time of release of this magazine it was not yet known if that goal has been achieved.

Questions for the **Minister of Public Health Bruno Bruins**
On December 11 of this year, two Ministers of the House of Representatives named **Maarten Hijink** and **Henk van Gerven** (from the Socialistical Party) asked questions to **Minister Bruno Bruins** about the accessibility of physiotherapy forME/CFS (among other) patients:

What do you recommend to Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome and rheumatoid patients who are in need of frequent physiotherapy to maintain their health, but who cannot receive reimbursement for this treatment from their basic health care insurance package, and from 2020 on also cannot apply for supplementary health care insurance as the medical selection for this supplementary insurance package will filter them out?" We are very eagerly awaiting the response of **Minister Bruins**.

Source: ME/CVS Vereniging

Pajamaparty
On December 31 Millions Missing Holland organized a virtual pajama party, this was their announcement: Join the New Year's eve pajama party virtually! Are you home- or bedbound, or in a post Christmas holiday PEM crash? Can't make it to some NY's party? Those who cannot make it, can fake it by joining this event. Post your favorite song, a message to the ME community or a fake party image under the event or on your own timeline. This year you can also enjoy our bedwalk with your most fabulous pajama outfits (you can send them as a message under this event).

At New Years Eve please add the hashtag #PJparty #FakeJeFeestje #FakeYourParty. We love crazy party pictures! 57 patients participated.

United Kingdom

ME Research UK

In recent months, ME Research UK has awarded funding for two new research projects looking at different aspects of ME/CFS.

Investigating sensory processing and cognitive function in people with ME: a pilot study

Dr Sanjay Kumar, **Dr Farzaneh Yazdani** and colleagues at Oxford Brookes University are interested in the phenomenon of hypersensitivity – when the brain's ability to process sensory information from the surroundings is impaired, leading to a disabling hypersensitivity, affecting individuals' ability to take in information and make decisions.

Although hypersensitivity is not considered a primary factor in the diagnosis of ME/CFS, it is a common finding in people with the condition. This was borne out when the team met with people from a local ME support group, many of whom identified with the issue and said that it interfered with their daily life.

This prompted a series of investigations to understand the nature and impact of the sensory problems experienced by people with ME/CFS, and to determine whether they are associated with any functional or electrical changes in the brain.

The team aims to assess patterns of sensory processing and how they affect functional performance in a group of people with ME/CFS and a control group. Following a questionnaire-based assessment, the participants will complete a series of neuropsychological tests to investigate a range of cognitive processes, while the electrical activity of the brain is measured non-invasively.

The investigators' hope is that the results of this preliminary work will help in our understanding of the brain mechanisms that underlie the abnormal sensory experiences of people with ME/CFS, and also lead to the development of interventions to help manage these problems.

Role of Sirt1/NOS axis in vascular and immune homeostasis: a missing piece in the ME/CFS puzzle?

Dr Francisco Westermeier and colleagues at FH Joanneum University of Applied Sciences in Graz, Austria are exploring the potential impact of immune abnormalities in ME/CFS. Inflammation is part of the body's defence mechanism and healing process, involving an increase in blood flow to an injured area and aninflux of immune cells into the tissue to repair damage.

But sometimes inflammation can persist for longer than required, or be triggered unnecessarily, and this may itself cause damage. Inflammation has been implicated in a number of conditions affecting the cardiovascular system, specifically its impact on the function of the endothelium. This is a layer of cells lining every blood vessel involved in controlling their opening and closing, and hence the amount of blood flowing through them.

One of the ways the endothelium controls blood flow is through the release of a chemical called nitric oxide. But nitric oxide is a double-edged sword – while it is essential in normal endothelial function, too much can be damaging and lead to prolonged inflammation.

Dr Westermeier is exploring this complicated relationship in more detail by looking at whether the cellular mechanisms that control nitric oxide production are altered in ME/CFS.

Using blood samples obtained from the UK ME/CFS Biobank, he will assess levels of nitric oxide and the proteins involved in its production. He will also investigate whether this is altered in endothelial cells that have been exposed to blood plasma from people with ME/CFS.

The researchers hope their findings will throw new light onto the role of these complex mechanisms in ME/CFS, and possibly identify new biomarkers of endothelial dysfunction in the illness.

Dr Westermeier says that ME/CFS is "still poorly recognised in Austria, in part due to the lack of funding and research". He hopes this project will also help raise awareness of the condition in his country.

Biomedical Trustees

ME Research UK is currently looking for an individual with experience of medicine or relevant scientific research to join its Board of Trustees. The existing Board of six people has a diverse range of experience, skills and expertise, and it wishes to add to the knowledge of science and medicine within the Trustee group. Potential Trustees will have a strong empathy with the charity's mission to commission and fund scientific (biomedical) investigation into the causes, consequences and treatment of ME/CFS.

If you or someone you know is interested in applying to become a Trustee of ME Research UK, please visit the charity's website for more information:.
http://www.meresearch.org.uk/biomedical-trustees/

Breakthrough magazine

The electronic version of the Autumn 2019 issue of Breakthrough magazine is now available online. You can access it at ME Research UK's website: http://meres.uk/BrThMag

The contents include ME Research UK-funded research on brain function and connectivity, sensory processing in ME/CFS, and nitric oxide production; short items on rituximab and the retirement of **Vance Spence**; and many shorter 'research bites'.

The magazine is free to patients and their families, clinics, academics, and research groups, so please email us with your address if you live in the UK, are not already on our mailing list, and would like a printed copy: meruk@pkavs.org.uk.

Submitted by **Dr. David Newton**

12. Petitions

Demanding US Health Agencies to Recognize ME as Defined by ICC

Sign this petition: https://bit.ly/2SSo1Mm

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: https://bit.ly/2u4tPYT

European Petition

European Petition for recognition and significant funding of biomedical ME-research continued

All European citizens can sign (so also all British, at least until 31 Jan.), also on the signatories list (see picture below), which you can download, fill in, sign (or have it signed by max. 6 pple), scan and send to eu.me.petition@gmail.com

Best is however to sign directly via https://bit.ly/2kpbrWd, as those signatures reach the Committee directly.

The petitionary, **Evelien van den Brink** wrote in October:
"The meeting of the Committee on Petitions on 3rd October 2019 in which petition no 0204/2019 was discussed has made a significant impact.

The decision of the Committee to keep the petition open and monitor the needed progress, was very well received by the patient community and seen as a valuable start to bring about real change for people with ME.

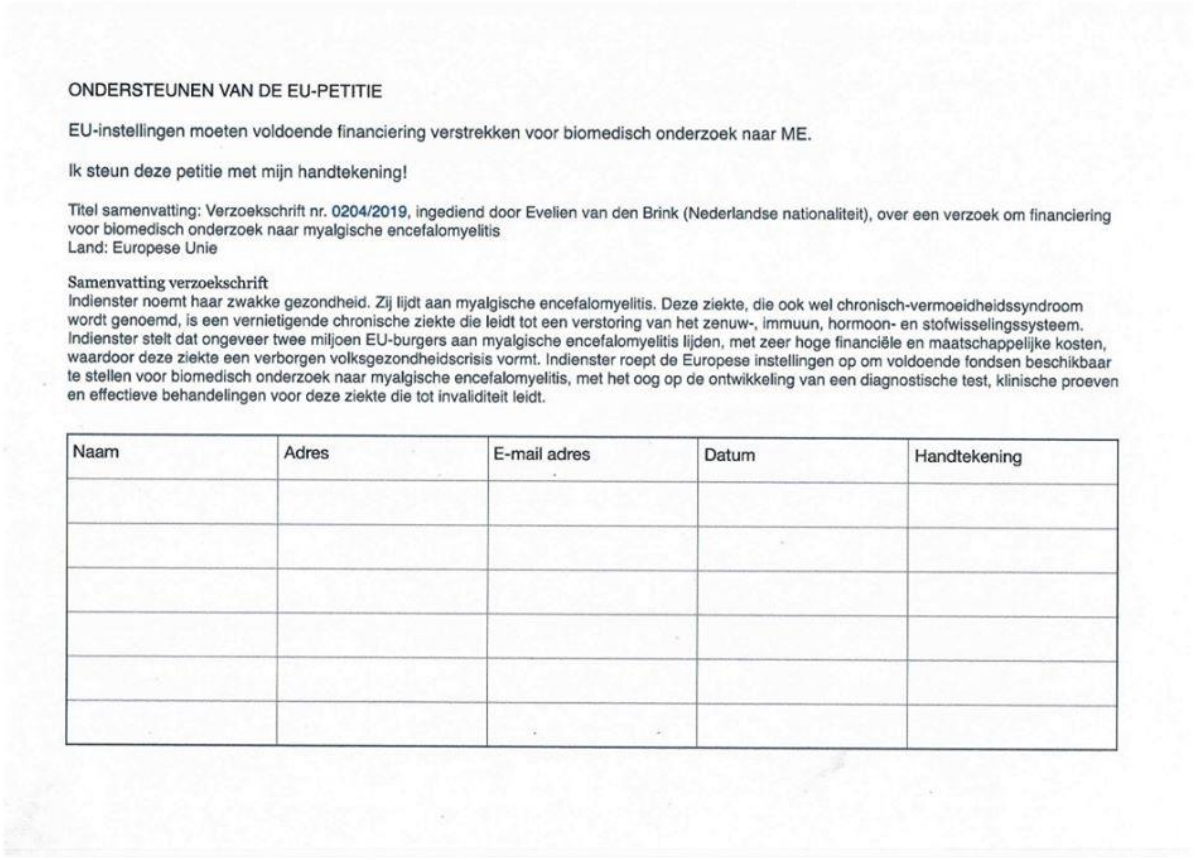
There is so much enthusiasm and support for the goals that were mentioned that will help to achieve the scientific progress that is so desperately needed.

Key to succes

The most important key to success will be the criteria that are used to select the patients for scientific research.

I would like to request that the use of the Canadian Consensus Criteria (CCC 2003) and/or the International Consensus Criteria (ICC 2011) will be included as a fixed condition for studies to receive funding. The CCC and/or ICC should be adopted until better criteria and/or preferably a biomedical test exist that will ensure reliable patient selection.

This would guarantee the reliability, homogeneity and quality of the scientific biomedical studies and make sure they are mutually comparable. I cannot emphasize enough how important the selection of the right set of patients included in scientific studies on ME will be."



ONDERSTEUNEN VAN DE EU-PETITIE

EU-instellingen moeten voldoende financiering verstrekken voor biomedisch onderzoek naar ME.

Ik steun deze petitie met mijn handtekening!

Titel samenvatting: Verzoekschrift nr. 0204/2019, ingediend door Evelien van den Brink (Nederlandse nationaliteit), over een verzoek om financiering voor biomedisch onderzoek naar myalgische encefalomyelitis
Land: Europese Unie

Samenvatting verzoekschrift
Indienster noemt haar zwakke gezondheid. Zij lijdt aan myalgische encefalomyelitis. Deze ziekte, die ook wel chronisch-vermoeidheidssyndroom wordt genoemd, is een vernietigende chronische ziekte die leidt tot een verstoring van het zenuw-, immuun, hormoon- en stofwisselingssysteem. Indienster stelt dat ongeveer twee miljoen EU-burgers aan myalgische encefalomyelitis lijden, met zeer hoge financiële en maatschappelijke kosten, waardoor deze ziekte een verborgen volksgezondheidscrisis vormt. Indienster roept de Europese instellingen op om voldoende fondsen beschikbaar te stellen voor biomedisch onderzoek naar myalgische encefalomyelitis, met het oog op de ontwikkeling van een diagnostische test, klinische proeven en effectieve behandelingen voor deze ziekte die tot invaliditeit leidt.

Naam	Adres	E-mail adres	Datum	Handtekening

Name – address – email – date – signature.
If one or more of these data are missing, your signature isn't valid

13. Poem - Faces

Faces

I get confused sometimes
by the masks I wear
I can't always tell
    what is Mask
    and what is Face.

Is Mask the one
    that says "I'm fine"
    that smiles and laughs
    that listens and engages and
        lives

Is Mask the one
    that says "I can't"
    that trembles and shakes
    that panics and worries and
        cries

I've got so
muddled
between mask and
face
I no longer know what is
truth

Is the lie that I'm fine?
Or is the lie that I can't?
Am I lying to others?
Or to myself?

Caro

Source:The Mighty https://bit.ly/35ND8Lf

14. Connecting You To M.E.

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

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

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

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