

Challenging Scientists to Make Myalgic Encephalomyelitis Front Page News

Since most physicians and the public at large do not believe the illness is crippling and "real", the illness must be taught at medical schools and more ways to get the information out to the public is needed. Only then, will researchers possibly be interested in using their research skills and time on ME/CFS. I think if researchers knew the extent of the suffering of severely affected patients they would be interested.

Relevant Health portfolios around the world need to take the lead and undo 35+ years of negligence by issuing RFAs for meaningful research that will advance scientific understand of Myalgic Encephalomyelitis. The amount of funding ME should be getting annually, to be commensurate with disease burden, is \$200 million in the USA alone. Currently, this funding is being spent on Fatigue Studies with Fatigue Criteria for Fatigue Patients which is insufficient for those who actually have Myalgic Encephalomyelitis. M.E. is a disease of the Central Nervous System not fatigue. Better defining is required. Hundreds of conditions lead to Chronic Fatigue. That is not the same as an Enterovirus attacking the central nervous system leading to brainstem encephalitis or encephalomyelitis.

The biggest barrier is the paradigm of it being a psychological illness that prevails - the research needs to provide EVIDENCE based biomedical research that is more compelling than the (often discredited) psychological/behavioural studies. The research needs to be coordinated better - not carried out in isolation. Researchers are finding some similar things and these should then inform the future direction of research - rather than individual studies getting lost along the way. Increase pharmaceutical interest in the illness.

A major challenge is the lack of recognition that patients are doing too much and need to rest more to stabilize and/or improve. The physiological data is needed to quantify the inordinate amount of rest needed and to make the disease visible. Once visible and measurable, research funding is more likely to follow. Exercise intolerance is the cardinal symptom of Myalgic Encephalomyelitis and research into this aspect is disappointing as it isn't required for fatigue criteria.

Stop the stigma that ME is psychosomatic. Educate doctors and public health officials that it's a neuro-immune disease with dysfunction in the immune, neuro, endocrine, metabolic systems. Educate doctors on the primary symptom, Post Exertion Neuro-immune Exhaustion, and stress early intervention of rest and to never push beyond energy capacity. Fatigue doesn't cause patients to become bedbound for years because they walked 10 feet from bedroom to bathroom or sat up for 5 minutes.

Educate every medical practitioner about ME. Doctors MUST take this disease seriously and put up dedicated funding. The community cannot continue to have the funding given based on donations from the different collaborative institutes. That is not sustainable. Funding must collaborate with all scientists in the field. This is a multi-system disease and people with ME have severely damaged immune systems. Convince scientists of the need for funding to research various aspects of the whole body illness.

Need to dispel myths about ME to medical community and create incentives for those continuing medical education credits to get patients diagnosed so that they can participate in studies and medical students should be taught about M.E. to build interest into research.

The biggest barrier to progress in this disease is the medical community's refusal to accept it as a disease at all. Education of the greater medical community to recognize this devastating disease would be the key to establishing the will, in order to find relief for these patients. It is mind boggling how many studies are being regurgitated repeatedly using year's old studies to make it appear that they are progressing. The use of patient cohorts needs better participation selection. Stop mixing patients with Chronic Fatigue and Myalgic Encephalomyelitis together using Fatigue Criteria.

Older studies about ME are being manipulated to include CFS. This is part of an Agenda and it's narrative to try and sell CFS. This is biased science and doesn't help anyone except those who want to increase their social media presence. Many patients are self diagnosed and researchers aren't checking their medical history. Studies using this method aren't helping those with or without ME. The other thing besides more funding, is specifically drawing from related fields that are developing drugs for related conditions -like for example drugs being developed for mitochondrial myopathy, and testing them in ME patients, fast tracking any drugs that look promising because we have no drugs. MS, Parkinson's, Post Sepsis and insect borne encephalitis share some of the same symptoms as M.E. and studies for these diseases may be helpful.

Public health authorities should be open to discussion on monkey cytomegalovirus contamination of some of the licensed polio vaccines. They should be willing to confirm the published findings by culturing viruses from at least a few patients. They should also acknowledge the bigger issue of stealth adaptation as an immune evasion mechanism. Acknowledging the existence of stealth adapted viruses will raise national interest in the ACE pathway as a non-immunological anti-virus defense mechanism, applicable to both conventional and stealth adapted viruses. Acknowledging the existence of stealth adapted viruses will also lead to progress in other neuropsychiatric illnesses.

Disseminate as much research and facts of ME to both doctors and patients, to increase the patient's support systems. Friends and family unfortunately believe a doctor over their own family member - so when the doctor is wrong - the suffering of ME is made 10 times worse for the patient. Stress exacerbates the symptoms.

Collaborate with the community, and the general public who have been touched by these illnesses, ask them for ideas, visit ill people in their homes.... otherwise how can you access the full picture? Not everyone seeks doctors, not everyone is on the computer, and not everyone can be bothered to reach out. -use more creative people not just scientists! This illness requires a wider approach and more creativity. ME patients can see how scientific research is clumsy, is failing. Get into the streets of the communities that you are serving, talk to everyone and not only the charismatic high profile patients who are financially subsidized to sell a chronic fatigue agenda. The main barriers to furthering this research are the GPs. How can this problem be seen in its real light if most of the people who are in fact ill, are told to go home because it's all in their heads? If the real number of ill people can come out in the open (GPs assess how many of their patients have ME) it would be taken more meaningful. Public Health mandates and Medical Anthropologists are in the best position to collate in depth analysis.

A proactive, accurate and concerted effort is required to educate researchers, the public and doctors about the realities of the illness. Align current billing codes with the WHO ICD to measure true prevalence and its debilitating impact and the lack of effective treatments would encourage more to enter the field. It needs to be led proactively in every country, not just waiting for grant applications to come forward. Reach out, advertise, educate and offer incentives people to enter this field.

Encourage global uniform data collection and analysis - then develop and pursue hypothesis from that data. But the biggest obstacle for patients and progress in research is the lack of a sustained and profound effort towards clinician education. Like the saying "If you build it they will come." There are thousands of primary care doctors, specialists, and nurses who would participate in organized data gathering and provide anecdotal patient stories for researchers - if they were MADE to understand the prolific nature and enormous burden of this disease and it's various patho-physiologies. Many patients are highly educated and would help free of charge.

Entice researchers from an array of backgrounds during their educational training; for example, include medical sociology students as well as medical students. Circular thinking by a group of 'like minded', similarly trained individuals limits the creativity and problem -solving abilities of a group. Encouraging education of patients and doctors to think outside the box leads to an increase in advocacy; increased advocacy will lead to increased awareness, which in turn will propel funding.

Finalize the one set of criteria that all researchers must use: ICC 2011. Using Fukuda to diagnose defeats the purpose as it is only a research criteria or SEID which is clinical only, is a barrier to progress which can be easily remedied. The lack of a consensus research case definition is a fundamental barrier to progress and quality research and replication.

The research teams need more money to hire and retain scientists, to invent, to experiment, to study the patient population. There needs to be more monetary incentive to get more researchers involved, new talent and there is a need for cross collaboration among specialties. There needs to be less stigma surrounding the disease and patients need hope as well as transparency. We want to see the research as it unfolds. There needs to be more government interest and support in finding the cure. There needs to be a bigger and better campaign to get the public involved. This needs to be seen as a health crisis just like AIDS was and given emergency attention. The government needs to invest big now and transparency will attract an increase of funding through philanthropy.

More neurologists and radiologists need to get involved since the brain is obviously affected. More hematologists need to get involved because mast cell disorders are a co morbidity: this also affected the brain and blood and organs. More doctors who look at the vein networks need to get involved because we all have flare ups and orthostatic intolerance. We can't walk upright or even sit upright at times because we have an enormous amount of pressure and pain that builds up in our heads. We get trapped in our beds for long periods of time, sometimes indefinitely.

Involve patients more in planning research there are many scientists and doctors with ME who would be able to offer relevant observations about potential research avenues.

- more funding
- overcoming psychosomatic lobbyism
- look out for subgroups for more accurate results
- better education in med schools. Young scientists now, take serious and have an interest in the disease.
- more accurate diagnostic criteria for studies (ICC)
- a way for severe patients to get in touch to provide research samples and participate in clinical studies.
- An international network of medical professionals assisting the collection of (blood?) samples.

Coalition, multi-focal (especially post exertion genetic-immuno-metabolic studies) and collaboration with the best Researchers, Doctors, Labs, technology and patients. Listen to patients and their symptoms because patients are the experts. Each and every symptom needs to be noted properly and acted upon. Patient experience and the way M.E. presents itself is an individual assessment.

Use of strict ME criteria to avoid researching those with fatigue from other unidentified illnesses and idiopathic chronic fatigue. Many patients are self diagnosed because their doctors can't find anything and neglect the patient's needs. The right universal criteria start with the family physician. If they can't find a reason for the patient's illness then refer them to someone who can. Patients should be re-assessed prior to research.

Autopsy based research for those who die from secondary causes. Myalgic Encephalomyelitis attacks our voluntary and involuntary organs. It is a primary diagnosis.

Growing the open collaborative efforts that are emerging & marketing the area as the exciting opportunity to solve ME & likely discover the keys to many other illnesses in the process. The emerging medicine has high potential. Awareness campaigns of the true impact of this illness & economic impact. Endeavour to find realistic numbers for patients suffering from ME and CFS to determine economic impact. Introduce the use of separate billing codes instead of combining them. The WHO ICD 11 has included viral caused CFS and ME under Post Viral Fatigue Syndrome. They haven't listed it as ME/CFS and Chronic Fatigue caused by something other than a virus is excluded.

Reproduce results of valid clinical trials - the trials are often so small that they are not taken seriously. Work with findings already thoroughly established to have a connection - like orthostatic intolerance and low blood volume - and follow these to the metabolic and cellular level to find the root cause.

Focus on making the disease "visible" by quantifying and measuring level of disability. Focus on the low hanging fruit and lifestyle changes that yield immediate benefits. Heart rate pacing etc... that is known to be effective by clinicians and patients using it <https://www.youtube.com/watch?v=yKoheNZlqXg>. Be open to why alternative treatments help patients.

Define the disease. Research into Myalgic encephalomyelitis should use the International Clinical Criteria 2011 which do not require a symptom of fatigue. They do require post-exertional exacerbation/crash/relapse. This is the distinguishing feature of ME and any research which does not require it is useless to ME sufferers. Is research into cancer directed at cancer/CFS? Or MS as MS/CFS? etc. This is nonsense.

CFS is a separate disease. The CDC found that the Lake Tahoe epidemic was not ME, and it should therefore be researched separately. CFS is a vicious disease with a stupid name, like calling cancer a syndrome. Establish guidelines for diagnosis. Eliminate the idea that this is a mental disease or conversion disorder. Create access to specialists who are knowledgeable and willing to treat the disease.

We need more on how to care for these patients. I realize one may need to come before the other but some of us are desperate and dying a slow, painful, pitifully death. Every medical school needs it to be taught. Public awareness also needs to be improved. Doctors need to take patients and learn.

One of the most alarming things is how much ignorance and incompetence seems to be in the entire system of researchers and doctors. Many PhD's who specialize in FMT/microbiome being severely deficient in knowledge/insight in this field, not up to date with the literature, etc. Some of it seems to stem from the fact that much of their knowledge might be too specialized, and they're lacking broad knowledge/insight on human health and the gut micro biome impact on the entire body.

Good science. Do not fund corrupt scientists with conflicts of interests, or any involved in the PACE Trial Study. Bad science has set research back decades, longer if the bad science is sitting on top of the real solution. Spend a bit of time, google the scientists names and see if they've been involved in bad trials in the past. See if there are ongoing court cases against them and maybe, just maybe, think twice before throwing money at them or promoting them to lead all the research. Quacks are drawn to unsolved diseases. Think homeopathy and herbal medicine. Do not fund alternative medicine and corrupt scientists trying to profit over the suffering of desperate people. Double check the medical history of charismatic advocates selling questionable cures and/or trying to change criteria without the education and experience required to treat this debilitating disease.

Outreach to healthcare providers to reeducate a generation of doctors currently convinced that ME is primarily a psychological illness instead of a physical one, when the opposite is true. Also, spread the word to healthcare providers about the importance of:

- taking the illness seriously,
- maintaining contact with patients despite their condition being "untreatable,"
- locating and discussing with patients the availability of potential research studies for individual participation and
- increasing ways for ME patients to participate in said studies, despite facing limitations imposed upon them by the disease.

Work with all patients and not just popular FB groups. The majority don't understand Criteria.

**The biggest need is for scientific integrity and professional courage
in speaking truth to power.**