Other approaches that may improve the overall field of ME/CFS research

The only approach is to make researchers, physicians and the public realize that ME/CFS is a serious illness, as serious as MS and other neurological illnesses.

NIH needs to proactively issue strong statements against those who are still stuck in the past and bad science, arguing that ME is psychological and can be fixed with therapy and a little yoga. Recently, there was a Reuters article because British researchers (e.g., Sharpe and co.) are pretending to be victimized by patients and advocates who rightly criticize their bad, misleading and harmful "science." Can you imagine if they were arguing that AIDS could be addressed through exercise and therapy? That it was psychological and not physiological? That would be a dangerous thing to try to argue. And American institutions like NIH should issue strong statements about it. And then, they say that because their unscientific and harmful publications are criticized, they pretend they're being harassed. Good scientists attend to criticism. That's how science gets better. But they can't seem to handle it. When NIH researchers see this type of thing, they should say something.

Too much focus on tests and not enough on treating symptoms. There needs to be a paradigm shift in treating the patient and keep them within normal blood ranges.

individual based treatment.

NORMAL RANGES DO NOT TELL YOU THE CORRECT RANGE FOR THAT PERSON. TOO VAST.

More funding!
More priority!
Better targeting of 'types' of ME - eg in children, in first 6 months of illness, in long term sufferers. It is a 'mixed bag' that needs to be better differentiated.
Separate out other comorbidities like depression, POTS better - again - too much is lumped into the 'syndrome' approach rather than focusing on the key defining features of ME.

Teaching ME/CFS in Medical Schools.

Funding and more funding. Be on par with other diseases, not the minimal amount that it historically has received.

I think the best thing is to establish a biological marker and make it accessible to all clinicians, then we can establish how many people are effected through accurate diagnosis. When it is established that the millions of people suffering are without a doubt suffering from Myalgic Encephalomyelitis, then the publicity will follow because it will be evident that this is massive epidemic that the community has been saying it is all along.

Ditto

Establish a mentorship program to connect established, successful clinicians and researchers--especially those who are in the early retirement phase of their careers--with younger folks who are committed to making an impact in this disease of unmet need.

SKYPE and patient inclusion at all stages of research early pre design etc...get preliminary questions/ideas out to patients to ground truth early as Lenny Jason does. It makes a lot of work but the strengthening of his PEM survey is due to his wide and inclusive worldwide collaboration with patients.
Money. Apologies for 30 years of neglect. Acknowledging the debilitating nature of the disease and implementing early intervention of rest.
Whether the cure is confirmed within 1-2 hours is confirmed to anyone. It would be better to first establish a cure and then set it to the next research direction.
Listen
More money is needed for research. I have lost 30 years of my life to this disease. Family, friends, career, significant other, financial stability, social life, became infertile, etc...
TRAIN MORE DOCTORS, LOTS OF THEM. USE INTERNET INTERVIEW PRODUCTS LIKE ZOOM, GOTOMEETING, AND MANY OTHERS. Survey us, interview us, test us, we are hidden because we can't get around. It doesn't mean we can't get help traveling, it doesn't mean we can't talk through computers, we want to help you. Let us help you. Thank you for the email, thank you for the opportunity to provide a perspective. It could be we need certain nutrition, certain reconnections in our neurotransmitters, we don't know, but the medical and technological fields that are combined in this project are filled with bright minds. Give us a chance to help provide data. We only want part of our lives back, if that is the best we can get, we'll gladly trade time and journals to help find a solution.
We need an ME Task Force that has some bite. The President just brought back the Advisory Council on HIV/AIDS (PACHA)and made a commitment to end HIV/AIDS by 2030. It time for that to happen with ME. Who can make that happen? Fauci was part of those conversations. Ask him to bring up the need for additional funding for ME as we must end this epidemic as well. Maybe appeal to the fact that Trump has a daughter and could very easily get this disease?
Public service announcements dispelling myths and increasing awareness so that people get diagnosed and budding researchers are attracted to the field.
Much needs to be done in the area of education of the greater medical community. If the problem is not recognized, then there are so many patients falling through the gaps and a huge loss of opportunity to study this disease and develop clinical trials. there has to be a consistent protocol in place that helps identify patients who have deceloped this disorder so that they can be directed into research studies.

We need a ME/CFS-focused call for proposals R03, R21, and continue to use the ME/CFS focused study section. We also need to fund more junior investigators for innovative proposals.
Educate PCPs!!!!! See above.
-training and grants for sufferers, give them tablets and computers, give them access to community colleges, and ways to fill out forms to get into studying -create workshops retreats with sufferers and doctors researchers, we drink veg juice, have treatments like infra red - visit other countries where the use of alternative treatments are more popular like Ukraine, I found treatments like cycloferon, (an immunity stimulator) activated charcoal, very fresh probiotic paste, a huge array and variety of organic clean herbs in extract form, visit Ukraine and russia where they cure people in alternative ways.
ATTENTION! MONEY! FUNDING! ATTENTION!
PLEASE SEE ABOVE!
Money, communicating with the general public the way the do with cancer, heart disease
I am in ME remission after 1 year of weekly acupuncture. Maintaining remission is a daily, delicate balancing act that involves avoiding new viruses from travel, crowds, institutions etc, but if you want to send someone to my island home to do blood & other tests (that I can tolerate), I am willing to do that & share my 5 years of health records: sharpersona@aol.com PS I have the genetic mutations that prevent fighting off viruses so that is a useful test for new patients who are trying to get a diagnosis from doctors untrained in either genetics or viruses.
You need to make a proactive, national and international marketing, PR and funding effort to educate people, get this high on people's awareness, and show that you are committed to finding commensurate with disease prevalence and burden. This is of utmost importance. The decades of stigma and neglect surrounding this illness means that it won't take off on its own. Progress won't happen at the pace and scale needed without a huge, concerted, public effort from the NIH to correct misinformation and misperceptions, and to provide the large amount of funding required.
-As a patient caretaker, one of the biggest issues I encounter is a lack of education/awareness among clinicians and the general public. Funding for Public Service Announcements that communicate what ME/CFS is, its severity, prevalence etc. -Could the NIH coordinate with other organizations that would result in more education for providers?
Grow a conscience that would help.

There are most likely multiple triggers for the pathophysiological anomalies. Spending time and resources on cause is critical for the long term. For the short term, we patients need relief - whatever the original cause(s). Spend resources on alleviating the most common and disabling symptoms. PENE.
Creating a media packet complete with relevant contacts for the media to use might assist in overcoming the stigma that news organizations perpetuate. Stigma is important in this instance as the perception of this illness as a psychological disorder or replete with fakery is a major roadblock to progress.
Fund research at the med school level, utilize the professors for oversight and clinical diagnosis and identify the ME/CFS patients at the community level. Must start identifying the patients and getting them into the health care system with the correct diagnosis.
We need to engage researchers with other health paradigms , such as Functional Medicine, Integrative Medicine, Naturopathic Medicine, Environmental Medicine and Eastern Medicine. The traditional allopathic approaches are not effective in treating chronic, complex, multi system illnesses.
Get to know patients who have this disease. Ultra, Severe, moderate and mild. We can tell you what symptoms we have. You can tell us how it's all connected. Get to know the scientists already working on this, no need to start at the bottom. Get money. Get money. Get money.
Improved diagnosis at the patient's first doctor = more awareness and funding and also more chance of accepting Pacing early, before the patient's progress the disease by trying to "push through" - this is critical and it's missed. I, like too many, am severe because of this exact situation. With early diagnosis I could still have had a life, instead I'm house bound over 7 years and counting.
Have the CDC admit they dropped CBT and GET recommendations for the reasons given by the P2P and IOM. Finally meet the agreement to educate doctors on appropriate treatment. You can't use SEID, need to do as the Klimas, Montoya CME said - if SEID indicates probable, do exclusionary testing, use the CCC or ME ICC for other typical symptoms - can't ignore immune and neurological! Add to all medical schools, all journals...Mke Mayo and others who have harmful outdated info take it down. Get the IACFSME PRimer back in Guideliens.gov (pay them to revise it)
- more funding - better career chances for researchers - better educations in med schools - use ICC - no entry criteria or outcome measurements that are susceptible for bias. (e.g. Oxford, Chalder fatigue scale...)
Multi-focal studies including genetics, metabolic, pathological, immunology, neurology, physiological studies comparing post exertion and before.

Continued public relations work on changing that original, unfortunate name. Disease needs a face -- and one that does not simply look like a depressed teenage girl or tired mom. (And I speak as this cliche'd face!). Professionals, athletes, etc. who had to cease working or work through this illness.
Greater ring-fenced funding
Get Career Research Exercise Physiologists involved.
Money.
Doctor education NOW.
The more the reality of living with this illness is understood, the more motivated researchers will be. The more the reality of living with this illness is understood, the more motivated doctors and researchers will be. So one approach could be more advocacy-emphasizing clarity of message (just the basics) and personalizing the illness (think how much Jen Brea brought a spotlight on the illness).
Find it it's own home this working group approach is not working as noone has any ownership over people with ME/CFS.
You do need to exploit big data by collecting info from us, such as blood test results over time, development of cancer and heart disease, infections with various identified illnesses, reactions to vaccines, etc. The patients who have been ill for 30 years or more should not continue to be neglected as sources of valuable information.
Fair funding $200M/yr NOW!
-change the name -choose a scientist and name the illness after that scientist - or use this random name generator to select a name: https://www.name-generator.org.uk/quick/ -it doesn't matter the name, just pick one that doesn't minimize the severity of the condition - thanks :)
PLEASE help our underserved population! Condider a suicide rate study and prevention.
Appropriate significant sums of money designated solely for ME/CFS research and let it be known that this money is available. Streamline the process for applying for grants. Solicit the input of current researchers in approving grant proposals. From what I've read, the people who have been reviewing research grants aren't experts in the field, hence downright exciting grant proposals have been turned down. (Ron Davis, for example) Have grants reviewed by current experts, not people who aren't experts in the field.
England has at least one CFS/ME clinic in Birmingham, UK. It is a recognized diagnosis for disability over there. Are there other clinics over there or in other countries? Do they have information to share internationally?

Reaching out to communities, universities and the medical field at large to educate and share the challenges.
Getting med student involved at any level is a plus for the future, they may stick with it after doing it part time or for credits. They need to be exposed to it and the mystery of it. Get students interested in research and if their miner is in law , Marketing ,Business . The earlier you can get them the better for the future. Them and their classmates may well be the future of this. Going ene to the level of Seniors in high school, I would have given my eye teeth for that opportunity. Only take the most serious student and the ones that have the best grades in biology and chemistry. The idea is to get them started in this endeavor early and keep them.Ciggerate comanies get teenages to smoke so thay have a lifelong customer.Same thing, except their love is science and research.It was like a drug to me. Students that don't have the finances to go to college but can get on the job training. If they are good, provide their training in exchange for a set amount of year of research in your interests. After that time, they may stay but either way it is a win/win for both of you. I hope I have offered something of value, and not just words, you are far above me in knowledge, but just brainstorming here. thx for asking.
Awareness awareness awareness. I cannot stress this enough. By increasing public awareness more patients will come forward to tell their stories and participate in studies. We could actually learn from each other instead of wandering through a medical world we don't understand for answers. The lack of validation created by the current unacknowledged state of ME/CFS will keep millions suffering in the dark alone.
No input on this point.
Each medical educational institution, hospital or center of competence should have professional with different expertises working together. At this time, there are too many silos. The conference at the NIH was good because it brought them together to share ideas, but the question is how will these ideas be followed up on and who will be the leaders who will create the centers of competence.
And again, massive increase of funding.
Educate DOCTORS. Make them believers. They may need incentives to educate themselves, or at the very least, a reassurance that their jobs are safe even if they acknowledge chronic illness.
As you can see, the answer is quite simple. I'm convinced that there's only one solution; Increased funding. During the NIH conference Dr. Maureen Hanson challenged Dr. Francis Collins to fund ME as much as HIV. She said; 'You lose your life to this disease.' The level of funding for biomedical research into ME should be in accordance with the number of patients and the disease burden. It has such a profound impact on patients' lives. Scientists usually disagree on many things, but in this case all agree that the budget is far too tight to advance the field in an acceptable timeframe. What our scientists have achieved despite the lack of funds is exceptional and it shows that much more is possible at a much faster pace if the budget is raised to a realistic level.

If it's true what dr. Collins said in his speech and we really are family now I'd respectfully like to tell him; Dad, don't be so close-handed. My practical proposal would be to put the best scientists who have been studying this disease for the past years in one room and give them the assignment to come up with a comprehensive strategy to help us forward as fast as possible. Let them make a proposal. They know what's needed and they're all very much aware of the fact that they need to be economical. And then the most important part; Provide the needed resources. You could ask Prof. Dr. Ron Tompkins to lead the effort. Give him a grant following the example of the famous NIGMS Glue Grant that was used to unravel the complexities of sepsis. Let the scientists work in a streamlined way, a guided effort to really help us forward. I'm 34 years old now and I've been sick for 20 years. I want to see the end of this. Thank you.
Informing more people about the importance of clinical research trials in general, and how it benefits not just those researchers, but the goal is to find effective treatments and ultimately a cure for patients suffering. It is a win/win as I used to tell participants when coordinating clinical research trials, we are helping one another. Most often it is free treatments they otherwise would not get, and participants are contributing to this underfunded and overlooked but so important disease of ME/CFS that impacts millions and their families. People want to know they are making a difference and impact in this world, so we need to let them know how important this ME/CFS research is, and how they can help.
Shared above in my other answers.
I'm 71 years old and have been ill for 53 years, since having EBV at the end of my first semester of college in 1965. Please reinstate CFSAC - it offered our only opportunity to cross-pollinate through all NIH (HHS) departments - and spread progress in all arenas. I'd already sent one set of answers before the time for doing so was expanded. Thank you for giving us another 2 weeks - we needed it. Considering the disease burden and the decades of inadequate funding for research, expanding the Centers of Excellence (see above) seems reasonable.
Doctor education during medical school and/or continuing medical education of current doctors. If more doctors were educated about ME/CFS during medical school, and some of the stigma was overcome (ME/CFS is not deconditioning, depression, or fear of exercise), then maybe more doctors would choose to go into ME/CFS research. I am just a patient and I truly do not understand all the politics but I hope this is helpful.
More funding. Our lives have been cut off at the knees.

L.S.

This may be very important.

Is there a link between ME and Darier's Disease?

Yes: the calcium problem!

Several important ME CFS studies show:

calcium is a cause, and even can be THE cause of ME CFS.

Darier's Disease IS caused by a calcium problem.

Worldwide, numerous scientific studies have been published about Darier.

Authoritative scientists worldwide work in this field, with new studies.

Darier is a rare disease. You can have it without external characteristics.

It is mostly know as a skin disease, but it can effect every cell of the body: for examlpe in mucous membranes, organs, bones, blood vessels, eyes, etc.

There are hereditary Ã nd non-hereditary forms.

Both forms: most patients do not know they have it.

Or are diagnosed after decades (biopt, biopsy of the skin).

Only a few dermatologists and other doctors know Darier.

Patients have to educate their doctors.

Patients with both ME and Darier who inform their doctors often then are told by their neurologists: ME does not exist, your fatique and other problems are caused by Darier, because calcium is essential for the whole body, also for the brain.

Neurotansmitters, everything gets disrupted.due to the calcium problem.

Both ME and Darier have a stigma.

ME should be mental. And the PACE trial is a disgrace for science.

Darier is know as a skin-disease. Patients should be mentally retarded. A mythe, due to an early Darier study? The group of patients in that ancient trial consisted of family members who were mentally restricted by inbreeding.

Summarising:

Both ME and Darier are being studied worldwide.

There are multiple calcium-studies of both diseases.

Hopefully the researchers can work together succesfully.

ME CFS may be due to calcium problems.

Darier IS due to calcium problems.

(Darier's Disease is also known as Morbus Darier White, Keratosis Follicularis, Dyskeratosis Follicularis, or Darier)

A closer look at how patients report symptoms

Long-term ME/CFS patients know their symptom well and often better than researchers. This means they are a vital tool in developing and refining questionnaires and symptoms assessments. The development of the PEM questionnaire at DePaul University offers an example of how valuable the involvement of the patient community can be.

In-depth investigation of how patients describe post-exertional malaise, have shown it to be a not one but a complex myriad of symptoms. Some of these such as a delayed onset and prolonged recovery time may be characteristic of ME/CFS and help in differentiating it from related conditions.

Other symptoms such as cognitive impairment, orthostatic intolerance and light and sound sensitivity have not received the same in-depth investigation. These symptoms have mostly been recorded by singular questions or by questionnaires that were developed for other illnesses. A closer examination might reveal symptoms or descriptions that are distinctive for the ME/CFS patient population. A research team could, for example, collect all statements of how ME/CFS describe their neurocognitive problems, as specific and detailed as possible. They could then make an extensive questionnaire out of the responses and test it in related conditions to see if some statements are distinguishing of ME/CFS.

See comments above.

Thank you for your efforts!

Kind regards from Germany

-As a person with ME, one of the biggest issues I encounter is a lack of education/awareness among clinicians and the general public. Provide or advocate with the appropriate entity for funding for Public Service Announcements and major out reach to the medical community, that communicate what ME/CFS is, its severity, prevalence etc.

-Could the NIH coordinate with other organizations that would result in more education for providers?

Intellectual rigor. Do not confuse correlation with causation. Read the historic literature. Speak to and assess patients from earlier epidemics. Reject all trials/studies with subjective outcomes. Actometers and other measuring devices are available. Use them! Listen to patients and believe their experience.
FUNDING
Distribution of information to ALL doctors. It is incomprehensible that most doctors in the Boston area have no idea what this disease is and won't even try to treat it.
I wish I had more ideas.
Educate and up date all medical professionals. Make it compulsory. Teach CFS/M.E at all medical schools.
Education. This includes ME as a disease taught in post-secondary schools as well as in high school. For example, I would be happy to visit a high school science class when the focus was on disease and disability to tell them about how I went from a happy nurse practitioner to someone who was bedridden with this damnable disease.
Philanthropy of afflicted and non afflicted who care about these types of causes Awareness, promotion and programs allowing individuals to become more aware of these conditions and their devastating effects. Chronic illness and increase of SUICIDE awareness.
More more more publicity of the disease itself, and the needs
Money. Money. Money. Money.
Funding.
Educate doctors and public
Publicity and funding..publicity and funding. How about community fund raising like they do have for cancer and MS? We need a lot more education and people raising money..like a yearly run for CFS, and walk for CFS, or something to raise visibility.
Test the T4 conversion rate to T3 as it appears there is a big problem for ME patients' bodies to do this and this won't be tested for many ME patients who have hypothyroidism and are given thyroxine which I don't believe helps that much. Most ME patients have this condition for some reason and are often in the band of just within the lower normal limits for their thyroid which may not necessarily be normal to them. Migraines and mitochondria are also high on the wish list of ME patients' wish to feel much better to cope with everyday life.

Research into the genetics of patients would be helpful as both myself and my daughter have ME and I have heard of more families with more than one patient having the illness.

Any research into the field of ME/CFS will be appreciated by the ME/CFS community.

Many of the questions in this ROI refer to attracting researchers and young researchers to the field of ME/CFS research.

The reality is that ME/CFS is not only an orphan within the NIH, but amongst the highly striated clinical fields of medicine. There is no ME/CFS specialist or specialist to be seen. As such, young clinicians are exposed to patients on the periphery, and often treat them as peripheral. Treating a symptom or complaint. This won't change unless it's pathology can be indentified.

However, researchers pay attention to trends. The NIH, and the NIH Director, have the most powerful tool to change the trending views of ME/CFS by simply talking about the problem, the severity of the problem as often as possible, to as broad a group as possible. NIH conferences intended for ME/CFS stakeholders will do little to answer many of the questions asked in this form. Speaking about the problem briefly here and there will do nothing.

Bring it up more! Make pleas to the public. Talk to the press. It's not hard. It's cheap and the NIH is so lacking in this regard it's a derilection of duties. If you can't fix the problem, bring it out into the open.

Every year Francis Collins speaks directly to congress. He takes about initiatives in other diseases, and makes requests for funding. And yet, here on this massive forum, has he every brough up one of the most underserved diseases? The director should use this forum to speak to ME/CFS specifically, and more than any half measure, these words would provide change. Congress does listen, and so do researchers.

Listen to the patients , they live it everyday

Putting serious money from the public bodies will make a huge engagement possible. Turn all those who fight for and with the ME community heroes because they are. Make everyone proud to be involved, will lift everyone up and make them proud and happy to be involved.

Support clinical trials that makes sense such as Nancy Klimas’s model-based approach to ME/CFS. This trial is not only innovative but it opens a entirely new approach to finding treatments for diseases. The NIH should fund Klimas not because of ME/CFS but in order to assess the effectiveness of her novel model -based methodology for finding treatments for disease. (Isn’t the NIH committed to be a leader in innovation?)

What do I suggest might help us?

First figure out how much we are owed for decades of what many of us hope was unintentional (though mean-spirited) ignorance and abuse by HHS and The NIH which spread to private insurance and disability corporations which are required by law to meet the needs of their investors ahead of their customers. Perhaps the most egregious denials of coverage by privately funded organizations could be assessed fines to add to this project. We require an amount based on the estimated disease burden in reparations. This figure could be updated as more people living with ME/CFS are diagnosed. This should be regularly funded until our deficit is met, without the requirement to reapply from scratch each year:

Second, create and open many more Centers of Excellence all over the country staffed by people in every medical field and discipline. (Neurology, Gastroenterology, Infectious Disease, Rheumatology, Dermatology, Dentistry, Physical & Occupational Therapy, Nursing, Complementary Medicine, Social Services, etc.) with both newly minted and experienced General Family Practitioners for oversight and referrals. I suggest funding via all of the Institutes mentioned in my sixth paragraph. Creating a new Institute just for us might limit options for adequate funding.

Organize 'Vista' type programs within in every medical and related discipline to cover the loans and other validated educational debt of recent medical school graduates or indebted practicing physicians in exchange for working together and sharing research findings with each other at these COEs and the privately funded non-profit organizations which have been our only hope for these publicly underfunded decades. There should be publicly available clinics centrally located at each COE with experts in each discipline. Adequate and appropriate diagnosis and treatment should be offered to all who come, then help in applying for disability or other aid if needed. Medical, nursing and support staff (cleaning and food delivery) might also have access to dorms while in the program.

Build clean, mold-free housing at or adjacent to these COE's for those of us who have become homeless due to decades of neglect and the systemic abuse of our community. The most severely affected may need special sound and light free accommodations. Many of us who are still only mildly or moderately ill might volunteer for the least invasive, most ethically scrutinized research projects and very carefully arranged drug trials - exceeding all Helsinki Protocol requirements. There should be no pressure to volunteer, as this would be stressful. These requirements must be powerfully overseen. Such communities might gather a willing ME/CFS cohort for research more available as travel would not be required.

Those of us with financial resources, private insurance or Medicare/Medicaid could be billed for clinical care (whether living within the Center or having traveled to get there). Each facility would need a centralized active social services department to help with disability applications and the requirements of living, daily delivery of wholesome organic food based on the requirements of each person with ME/CFS, nursing staff to bring and infuse IV Saline or IVIG or whatever the on-site clinicians prescribe. We MUST be permitted to reject any suggestion we deem inappropriate without being labeled non-compliant. Should a cure be devised or found in something already extant, we should be helped toward our previous independence and these centers can then be expanded to include other illnesses that our research might help or have already helped to inform.

Although we each have our own version of this illness, our shared co-morbidities include elements that might be investigated under several NIH Institutes' umbrellas AND SHARED with each other. (I'll put some of my possibly unique experiences in parenthetic notes):

NHLBI: There's something going on that shows up in our blood and/or plasma and our red blood cells tend to be deformed;

NHGRI: We've seen evidence that some versions run in families, so there might be a genetic predisposition after one or some combination of stressors;

NIAMS: Many started having symptoms after a bout with an infectious disease & a high percentage of us have had allergies since childhood and have developed allergies and/or sensitivities to the drugs we've been given to address individual symptoms;

NIAMS: Rashes and the odd auto-immune reactions to stressors (Note: when I developed alopecia areata after a particularly stressful cataract surgery, I was treated by Dermatologists who also diagnosed the hidradentis suppurativa that had haunted me for decades following the birth of my oldest son);

NIBIB: for the advanced equipment required to see what Jarred Younger, Michael VanElzakker, David Systrom, etc. have noticed about our brains, Vegas Nerve system and PEM;

NIDCR: To incorporate information and suggestions for treating our shared incidence of TMJ (Note: I was very lucky that a Dentist I saw while in NY taking care of my mother happened to be a noted Dental Anesthesiologist who treated both my TMJ and the painful ulcers I get on one - OR the other, never both - side of my hard palate before a flare);

NIEHS: for those of us whose illness started with or was exacerbated by mold or environmental toxins...

NIGMS: To organize and evaluate what is learned within other specialties;

NINDS: covering the brain and nervous system which is the Institute within which some already believe we should be (although we are STILL not included under their A-Z lists under any name) and (Note, because my son's version included Epilepsy at age 26 following a cerebral hemorrhage at age 10 with such unusually intense muscle spasms that each seizure is followed by life-threatening bouts of Rhabdomyolysis);

NCCIH: in case they can find interim solutions while the other Centers search for cures;

NINR: to educate Nurses about our illness, especially school nurses and those in rehabilitation facilities to recognize and care for our shared and individual needs - like administration of IV Saline infusions, which address the low blood volume that can impact our quality of life and/or IVIG infusions which also help many of us.

HHS's Office on Women's Health is still the only Department I could find (other than the CDC) that lists our illness and it has always functioned with very limited resources.

I'd also suggest that EVERY individual Medical Specialty create a Continuing Medical Education (CME) program, perhaps using Jennifer Brea's 'UNREST' and/or Ryan Prior's 'Forgotten Plague' (not the one with the same name about Tuberculosis) with questions that must be answered accurately before credits are issued. All medical and adjunct specialty practitioners need re-certification every few years and if a decent number of credits could be offered that would aid in spreading awareness of the reality of ME/CFS as well as the stigma most of us have endured. There are few ME/CFS specialists in the country and those we have are aging, many have already retired. We are too ill to travel to get diagnosed, our cognitive issues impede or halt our attempts to organize appeals for any of the help we need. This has meant that most of us get no help or support at all. We are still disbelieved by most doctors in this country and stigmatized and labeled non-compliant when we drop out of the Physical Therapy facilities or pain clinics we've been forced to attend when the GET they insist we try worsens our condition forever (Note: the very mild warm water AquaTherapy I engaged in twice a week for less than a month in the mid-1990s moved my Fibromyalgia while I could still work, to full blown

ME/CFS).

Because of mis- and dis-information, some spread by our own CDC, and the stigma still rampant in every medical discipline, we have lost spouses, connections with family and friends, even the religious organizations that might help their own members in need, had to sell our homes, then become unable to cover rent in a downsized apartment. (There are several members of the peer-to-peer phone support group I call into on the Saturday nights I am well enough to listen who are about to lose their home or apartment and don't own a car they can sleep in.) We do not do well in shelters. We need clean, mold free environments. Though we often feel isolated, interacting with others is stressful and exacerbates our illness. Each COE should also offer free internet access, phones and television for those residents who can bear them as well as a meeting place for those mildly and moderately affected to meet.

What we hear is that we should be grateful that the NIH is funding 3 Centers of Excellence for the research for which we (and CFSAC, now defunct) have begged for decades. The combination of stigma, no source of support and no appropriate options for survival, it shouldn't surprise anyone that some of us lose hope and either just wither and die in place or commit suicide.

No one told any of us that we should have applied for Disability as soon as we began to become disabled, instead of cutting our hours over the years and working part-time, then less for many more years until we could no longer work at all and lost our jobs; this limited the amounts in the working quarters that are considered when applying for any of the programs that help the disabled as well as for Social Security when the time comes. Many of us worked at well-paying jobs for decades, but lost any benefit from those years because of having had to cut our hours and then find work we could do while cognitively and physically impaired. Our system is not set up for people with our version of increasing disability. Social services, once we've lost our jobs and our housing are equally uninformed and put off by our inability to describe or organize our work and medical history and condition by the time we first apply for help.

So there we are, isolated, often in great pain, still disbelieved and often dropped from the practices of the few doctors who accept Medicare and/or Medicaid for those of us lucky enough and in good enough shape to be able to apply for such help or food stamps with our increasing disability - or to respond to the automatic cutting of those benefits to amounts on which no human can survive.

I read (in a recent Forbes article) that if we've been seen upright or temporarily able to function in a picture on social media, our government plans to cut us from any aid or help we have in place. Our illness sometimes waxes and wanes. It can take weeks or months to prepare, then recover from a trip to a grocery store or a doctor.

I've probably left many ideas out of this post. I used to be a fine editor; am now unable to edit my own writing. Alas. Y'all have my most sincere apology for the length of this thing.

I suggest you listen to the OMF foundation and the SMSCI organizations and listen to repected ME/CFS researchers, like Nancy Klimas, Jared Younger, maureen Hansen, etc.

Do everything you can to undo the CBT/GET damage. This has HUGELY set back the field.

Don’t re-invent the wheel - How was this overcome for Parkinsons, HIV, MS....
Get rid of the quacks that publish nonsense
Reach out to general practitioners and help inform them about ways to identify and diagnose potential cases of ME/CFS using a common set of diagnostic criteria. Let them know where their patients can get more information and how they can refer ME/CFS patients for trial/study participation.
A forum, such as Science 4 ME, where patients and researchers can discuss their work together to truly and accurately include patients in research.
I realize I am coming across as sarcastic, which is not really my desire. Please know I have been fighting this horrible illness for over 25 years and am very happy that at long last more people are trying to help! God bless you all!
Mandatory medical education on mecfs especially for pcp internal medicine. How to diagnose OI. Ways to treat it. Immediately starting clinical trials for drugs to treat OI. These drugs are already being used off label. Need to fda approve them. More patients will benefit once it has that.
Fund it adequately. Arise from your slumber and make it happen :)
We need sanctuaries or country hospitals like to old TB sanatoriums where a person can heal in a safe place or function well enough to work.
Thank you so much for you efforts to make life better for this group of patients and all the best.
I believe more standardization is needed in selection of patients to be tested. They must fit one definition of ME only, which means we need one mutually agreed upon definition of the disease. That being said, under the umbrella of the one definition, there also needs to be subcategories to fit patients with differing onset, patterns of illness, and predominant symptoms. Also, standardization in other aspects of testing would help integrate data from one lab to another.
Early diagnosis and treatment. Ad campaign for some that doesn't get you $$$$$$ from big pharma but really helps living human beings who suffer continually, like me. Fund Open Medicine Foundation with no strings attached, limitations or restrictions to aid in your cover up. Combine ME/CFS with other disease research to diseases with similar root causes....Autism, Cancer, MS, etc .Please look to remedying the mistakes you made in the past. I had mumps as a child....no big deal. I can have an rough illness for a week or two, or one for a while lifetime and early death. Which one would you pick? I pick harmless childhood diseases like mumps, measles, ECT. As for the dreaded Smallpox, your agencies gave it to me when I got the vaccine. How's that for disease prevention. I haven't been the same since. Retrovirus. Treat retroviruses!!

If the info from UCSD and Griffiths University in Australia is correct, our cells are not getting the glucose/oxygen needed to get them to fire. If this illness affects every cell in the body, researchers will be looking backwards from many, many abnormalities. Someone need to take a flyer and study something like Round-Up pesticide. It's now used worldwide on everything we eat, and was introduced shortly before the Incline Village outbreak. The way it works is to mess with the mitochondrial DNA to kill the bugs. Symptoms mirror those with ME/CFS but any university considering studying it has Monsanto donations cease and legal cases threatened. The only good info thus far is from the NIH, who can't be intimidated, and it is staggering. Have at least one study working from a source studying forward, rather than a symptom backward. I've had the illness 30 years and have done more than a thousand hours of study, and feel Round-Up is the most unstudied aspect of ME/CFS. I don't care if you do a few small studies on it, or one big one, but I think it will bear fruit much more than following every single symptom in a reverse study.
Focus on helping ampligen possibly get through the fda with patient right to try laws recently passed etc?
Stop calling it chronic fatigue ..its so much more than that.
More funding. Open research - share (anonymized) data with other groups. Remove any exploitative individuals with a vested interest in their own products/services/funding. e.g. PACE trail, homeopathy, alternative medicine etc.
News coverage from NIH & CDC indicating the severity, name change & need for more research. State that this area has been neglected for over 30 years. Mention some of the findings that have been found (not fatigue). Doctors are the ones that need to know & it seems patients read research & most doctors do not have a clue as ME/CFS is not part of their curriculum. The only way to solve all of your problems is to let the world know.
MONEY, but I have no idea how to fundraise.
In my view, the simple answer: Guaranteed research funding, commensurate with disease burden, given to specific ME/CFS research centres (ideally many more than just the three that are currently funded by the NIH). The system of asking for grant applications is clearly not working. My view is that we need perhaps 10+ centres, each given $5-10M per year for at least 7-10yrs and who have autonomy over their research in order to truly stimulate and advance this field. I'm very grateful to the NIH for improving its involvement in ME/CFS, with the establishment of the research centres and recent conference. However, it's clear that much more if needed and I hope that positive changes are instigated as a matter of urgency.
Educate family and primary care physicians so they believe this is a "real" disease. I'm really sick of the physician eye-roll! Enough is enough after 30+ years.

See above
Widen the scope of detection to include each patients entire health history
There needs to be a big drive to train more ME specialist clinicians. Not enough clinicians know how to diagnose ME. This potentially leads to two problems: one, ill-defined cohorts (patients diagnosed with ME who don't actually have the illness) and two, a lack of patient volunteers (undiagnosed patients who don't know they have it won't volunteer for an ME study).
Apart from having a firm diagnostic test, increasing visibility and public awareness of the disease remains the greatest barrier to ME/CFS research and funding thereof. In addition to the suggestions above, please consider establishing more than usually active PR/outreach divisions and media engagement efforts as key to the work of research centers and studies, when such efforts do not conflict with research methodologies or best practices. To humanize the illness, separate from and in addition to direct research initiatives, consider lauching a "StoryCorps"-style documentary effort to chronicle the lives of ME/CFS patients, with said documentary effort legitimized, organized and hosted by institutions affiliated with the ME/CFS research consortium(s) -- possibly via medical ethics programs, or humanities departments that are part of the same institutions, where relevant and possible.
Apart from having a firm diagnostic test, increasing visibility and public awareness of the disease remains the greatest barrier to ME/CFS research and funding thereof. In addition to the suggestions above, please consider establishing more than usually active PR/outreach divisions and media engagement efforts as key to the work of research centers and studies, when such efforts do not conflict with research methodologies or best practices. To humanize the illness, separate from and in addition to direct research initiatives, consider lauching a "StoryCorps"-style documentary effort to chronicle the lives of ME/CFS patients, with said documentary effort legitimized, organized and hosted by institutions affiliated with the ME/CFS research consortium(s) -- possibly via medical ethics programs, or humanities departments that are part of the same institutions, where relevant and possible.
Funding.,
Using deep learning AI to analyze patient data, fed by a cultural policy amongst researchers and practitioners to ask any patient being tested whether or not they'd be willing to give their information to a database, accessible to the centers of excellence and other registered researchers and practitioners, which would feed the information to independent or associated researchers' Deep learning programs.
Shame the people responsible for public health. There is really no excuse for why this condition hasn't been given any serious consideration. If it had maybe we might have had some treatment's by now. Certainly I have found some. Mold avoidance helped me alleviate a large degree of my symptoms and so did gluten avoidance. And chemicals and drugs. I am sensitive to all of these things. All have to do with sensitivities. I would think if you could validate this phenomena in others the rest would follow. Cause funders would have no choice to allocate if the paridine chqnged from "well we think this is psychological" to "well we know this isn't psychological"
Money money money Education education education State Paid for media awareness campaign to undo the years of misrepresentions and neglect

You really must look at environmental variables - especially diet, sleep and WIRELESS. Wired technology is safe, fast and effective and probably one of the most critical things you can do for someone with problems with fatigue. Even if you have great diet and other lifestyle variables in place, getting zapped by wireless can limit the effectiveness of an otherwise excellent diet and lifestyle plan. I really hope you seriously consider all of this, the effect of these environmental variables is huge. HUGE!
Ramp up public relations. The cultural shift in the widespread acceptance that ME/CFS is a serious illness still has not taken place. Patients continue to report that clinicians don't accept that the illness is "real" and even if doctors accept the ME/CFS exists, they may not accept that the illness is seriously debilitating. Educate medical students. Educate doctors already practicing. Educate state and local public health officials. Educate members of Congress. Educate people at the NIH and CDC. A blogger and ME/CFS patient reported that not many NIH employees showed up at the recent NIH sponsored symposium on accelerating ME/CFS research. Is that true? Publicly discredit PACE study and pressure health organizations that promote PACE results as treatment to update their knowledge about the disease.
Functional medicine is well ahead of the curve in treating ME/CFS patients and their symptoms. Their protocols need to be looked at.
If there is sufficient funding, unified definitions, standardized questionnaires, the researchers will come. 1. We need to fast track this disease that has been so neglected, overlooked, wrongly handled. 2. Do not give any money to any researcher who would try to categorize ME/CFS as psychological, psychosomatic, depression, etc!!!!!!!!!!!!!! 3. Get an accurate definition for this disease standardized along with any subgroup categories defined that appear 4. Get a standard ICD coding for this disease (I keep trying to tell my doctor it is 93.3 ICD code, but he puts it under CFS 53.82
National leadership is needed to bring significant improvement in addressing ME through funding and research. Using the April Conference as a strategic rallying point, the NIH can facilitate national leadership provided there is genuine commitment behind those efforts through the meaningful engagement of patients, researchers and clinicians. Two years ago, I wrote Linda Tannenbaum that it was not lost on me that some of the fiercest and most successful funders, advocates and researchers are either patients or parents. I have been drawn to this field as a result of having ME and am committed to improving our understanding and ability to treat ME. The April Conference can be a turning point for a collaborative model going forward, action is needed and expected.

Begin a doctor ME education program based on the ICC and IC Primer so doctors can make the differential diagnosis of ME and stop misdiagnosing their ME patients with CFS, ME/CFS, SEID, or other overly inclusive conditions that are not not ME.
-Support important clinical trials such as Nancy Klimas's model-based approach to ME/CFS. This trial is not only innovative, but it opens a entirely new approach to finding treatments for diseases. The NIH should fund Klimas, not because of ME/CFS, but in order to assess the effectiveness of her novel model-based methodology for finding treatments for disease. -Support funding for trials on Ampligen and Cortene. Cortene presents a new drug, a novel hypothesis for ME/CFS, and now they have data.
Remove everyone form your Working Group who believes that 'ME/CFS' exists and replace them with better-informed individuals.
ME is an international problem. The US are taking a crucial pioneering role in advancing the field and ending the discrimination and stigma. Consider viewing ME as an international problem that needs to be addressed. Absolutely crucial is increasing funding for biomedical research that fulfills scientific standards: the magnitude needs to be near HIV/AIDS funding. There is no other way to get researchers, quality research and quality results with breakthroughs. Define ME as a priority research field - take a stand. Experience shows that both, money and priority, will enhance research very fast. Try to influence the research direction (the biomedical and scientific path) in other countries, e.g. by making clear statements.
Utilize every possible way to prevent suicides by people with CFS/CFIDS/ME
To summarize, it needs appropriate funding which continues to fail all of us, disseminating real information to every single person in America (mentioning that Unrest is on Netflix, and perhaps even buy ad space on television to quickly summarize the illness and even allow people to donate), more inter-medical field collaborations, and the acknowledgement of the severity of the suffering of the millions of Americans who have lost their entire identities and have been ignored for decades. If the true extent of our suffering is really acknowledged and readily advertised, I believe it would shock people to the core and initiate positive changes in the research field.
The NIH could use its influence to destigmatize MECFS among medical professionals. It could offer more funding especially in the area of pilot data, develop a DALY, help assign MECFS to a medical specialty, encourage teaching in medical schools. Creating a shift in perception could only help encourage researchers and most of all make life better for patients. While many researchers in the field now have a friend or family member who is ill, it's notable that ME/CFS was not their primary pursuit during their paths in education and training. This implies that people aren't *choosing* this field, they are generously filling a void created by an unmet need.

I believe this need is unmet because of stigma, specifically within the medical community. (See #5.) The NIH is a respected authority. My physician friend says, “it would absolutely make a difference if the NIH threw its weight around.”
Think about deliverability. E.g. can a proposed diagnostic test be delivered at as low cost and therefore be accessible to more people? A high tech diagnostic test may be useful for a limited group of researchers/patients; however, it will not benefit all patients if the cost is prohibitive. Counterintuitively a test with a high validation cost may be the cheapest opting for patients; since the cost of the diagnostic test may be much lower than other technologies. Focusing on delivery may help to identify the key research areas/best options to fund. Expand the NIH study i.e. increase the number of participants. Publish data on other diseases which are incorrectly diagnosed as ME - this may help patients/clinicians/researchers.
Patient identification and diagnosis Physician and health care provider education Epidemiologists
Make it interesting and inviting for researchers, medical community, news media, philanthropists, investors
1) The ME/CFS working group needs to have a clear charge, deliverables, accountability, and an actionable VISION for scientific and clinical progress. 2) There is a lot of unmet need and confusion about where individuals with ME/CFS and related disorders can find medical and psychological support. NIH should promote the development of a help-line particularly for individuals without a specialist or who don’t know where else to get needed help or support.
Generally increased education regarding the disease, significantly increase research funding and enhance collaborations among related researchers.
NIH research funding to commensurate with disease burden, campaigns to fight stigma
In order to bring in more researchers and gain the attention of doctors/hospitals, we need the full commitment of the NIH toward finding a cure for ME/cfs by investing $200 million a year in research funding through RFA's. This is similar to what is spent on Parkinson's and MS. When the NIH sends this signal to the research/medical community such as they have done with AIDS, the medical community will surely respond. Recently, my friend asked her niece who graduated with a PHD in medical research what area she would focus on, the niece responded: Alzheimer's! My friend asked why, the niece responded... well that is where the funding is!!!
Not really. I already think you all are doing an incredible job in helping ME reseach accelerate. Thank you so much to all of you from the bottom of my heart.
Significant education of physicians about the symptoms, needs and challenges of those with CFS.

Designate a specific Institution to take responsibility for the disease. If it's unclear and there are no takers, I think there's precedent to place a disease in NIGMS until things become clearer. As that Institute supports basic research, research that crosses organ system boundaries, and capacity building, it could be a good fit.

Develop a strategic plan for the disease, in collaboration with patients, researchers, and clinicians. Follow up.

Generally, take a cue from rare disease research, (39) and any areas where NIH has successfully increased funding, researcher count, and availability of health services and patient satisfaction.

Specific funding announcements. Grant review that does not compete with better-understood and better received diseases, and is reviewed by people with specific relevant expertise.

Either work through your opposition to ME (it's historical; just live with it until there's evidence for a name change), or change the name to something else that doesn't include "fatigue" and sits well with patients. "Fatigue" is too vague/confusing and has a result of misdirecting research into a vague and unhelpful direction.

Cooperate with advocates, clinicians, and researchers to get a more appropriate diagnostic coding proposal approved. (Need a reasonable, distinguishing name at the top; appropriate exclusions both in "our" section and in sections that these patients should not be erroneously put into, etc.; Stay in neurology unless there's compelling evidence for something else.)

Hire some/more FTEs whose main job is ME/cfs.

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This is a neuro-endocrine-immune/intracellular/metabolic disease. Connections are needed between all of these areas.

Education modules need to be made available and heavily publicized to every teaching hospital in the US.

The CDC needs to give a public service announcement regarding the seriousness of ME/CFS with an emphasis on no longer recommending CBT and GET.

Patients with this devastating illness are routinely being dismissed and neglected and this simply needs to stop.

Mixing patient groups together who do not have the same symptoms has led to mishandling of the research and clinical care. It is time to use the ICC to diagnose the patients who fit that criteria and separate them out of the group of patients who do not fit that criteria.

This one fix will go a long way to improving research and clinical care for the ICC patients.

The usual approach clearly does not work, this disease defies the standard mould of medicine. Whether this means changing the usual ways or creating exceptions for diseases that do not fit the usual approach is a complex and far-reaching discussion to be had. Nevertheless, the round cog does not and will not fit neatly in the square peg.

What this means for the future is unclear, but this needs to be acknowledged, especially as ME is not unique in facing this reality of does not fit neatly in the usual categories and methods.

The status quo is a complete disaster and requires a significant course correction at every level.

More advocacy and education in both the medical field as well as within communities.

MORE FUNDING that is consistent with the large number of people affected by ME/CFS.

Either NIH or working with CDC/HHS/ or any powerful leader: Approach Graduate Medical Education to include in medical school curriculums. Sponsor CME with MEcfs experts educating clinicians. Make this disease reportable to Public Health to track the magnitude of the problem. Blog about this disease frequently in NIH blog, and twitter and scientific publications. MOST OF THE MEDICAL PROFESSION AND PUBLIC DOESN'T EVEN KNOW THIS IS A DISEASE. Leadership could change this rapidly. But do we have leaders or politicians. Include questions on the Medical Exam Board Questions.

ASK MALCOLM GLADwell or DAVID brooks to write a book on the history of this disease.

Sponsor Walk/Run for MEcfs events, raising some money, awareness and promoting fitness for those blessed not to have the EXERTION INTOLERANCE disease (MEcfs).

Get big pharma interested in this disease.

Develop an informative video that members of study sections reviewing ME/CFS proposals are required to watch, one that informs them of the serious, life-limiting, and biological nature of the disease. Otherwise study section members may know only what they have vaguely heard in the popular press about the disease being fake and unimportant.

Build on the work of NIH's Dr. Daniel Reich and his important study of the brain's lymphatic system. Investigate the work of Dr. Ray Perrin of the UK, whose three decades of study involve lymphatic drainage problems in ME/CFS patients.

Other Approaches

Energy Work.

This is a video by Dorothy Rowe, I woman I have worked with for 2+ years.

The video is Healing to Nourish and Strengthen Eyesight.

At 3:30, she talks about asking the system for energy and it only being able to provide some of the energy required, which struck me as consistent with how so many people with ME/CFS describe their particular version of fatigue-as if their battery only charges up to 5 or 10%-then she continues to speak about sub-cellular metabolism.

At 6:30, she talks about mitochondrial function, which seems related to the mitochondrial dysfunction of ME/CFS.

https://www.youtube.com/watch?v=HCD13ywJTKY&list=PLsNt0lIj9RdJwE_bG5mPyIY2udcI-7r8k&index=12

Creative/Other Expressions of people with ME/CFS as part of awareness campaign(s)

Approaching celebrity figures in pop culture to champion the ME/CFS cause in order to fuel awareness and increase chances of retaining funding. Everyone is 6 degrees away from someone famous.

Space Engineering/Space Exploration. 3-D Printing, Robotics, Silicon Valley.

It would be interesting for the Trans-NIH Working Group to assess the knowledge levels of program officers, Directors, and other staff at NIH regarding ME/CFS. Historically and extending into the present day, unlike many medical conditions, most scientists and clinicians have never been taught about ME/CFS or may have been exposed to incorrect or obsolete information. All NIH staff have the potential to help advance the field: program officers are often the frontline contacts for extramural scientists, Directors may influence what is prioritized for an institution, and staff work together to figure out allocation of funds. However, if they don't know much about ME/CFS or hold wrong ideas, it's no wonder that progress is so slow.

Another group to assess are ME/CFS grant application reviewers. While most members of the ME/CFS SEP likely are scientists who research ME/CFS, not all may be and it is vital to recruit people with expertise in other fields to evaluate grants when those grants have features that overlap with their expertise. Besides asking potential grant reviewers if they have ever heard of ME/CFS and how knowledgeable they consider themselves to be, it may be helpful to ask or remind people to be open-minded about what they are reading. The latter might seem odd but at least one member of the Board has served on various federal and non-governmental panels where scientific advisors were asked to recuse themselves if they felt they could not be objective with their evaluations.

For the past three decades, ME stakeholders including patients, advocates, medical experts and CFSAC members have given countless recommendations as to what should be studied to enable scientific progress for the disease.

This was done in the form of working groups, CFSAC meetings, P2P meetings - including written and oral communications from patients, advocates and medical professionals as well as community driven petitions. None of these recommendations were acted upon or funded.

In September 2013, ME clinicians, researchers, and advocates wrote open letters (experts' open letter and advocates open letter) to HHS urging them to cancel the Institute of Medicine (IOM), now the National Academy of Medicine (NAM) contract to redefine and rename the disease and instead adopt our ME experts criteria (the Canadian Consensus Criteria (CCC) with the aim of working toward the adoption of the International Consensus Criteria (ICC)).

HHS ignored and defied the voices of the entire ME community and refused to heed their crucial recommendation. Instead, HHS opted to use, disseminate and educate with an inferior, overly broad

definition - SEID!

Link to letter:
https://drive.google.com/file/d/1YflS5nPs89X9dHdrDRIXWGQR_N9H3ifu/view?fbclid=IwAR3ehJduKKG73lvFdj4jW2i4G1y0s2r4IfoQjSMa3wxhVUNZdtsAgZXzyBI

ME (ICC) stakeholders should be included in all HHS/CDC/NIH decisions. Nothing about us, without us!

The only way to accomplish meaningful change is for HHS and NIH to make a huge financial commitment into this devastating disease commensurate with what HHS and NIH have done for people with HIV/AIDS.

When investigators see that HHS is investing appropriate funds to support patients and study myalgic encephalomyelitis as described by the ICC, they will certainly come to this promising scientific field.

This is apparently a chicken or the egg situation. The NIH is unwilling to fund applications and researchers stop applying after being rejected and burned over and over again. The answer here is for the NIH to commit to a fixed number, say $50 million for FY2019 and approach the researchers who need the money. There are no shortage of big players in this area for this level of funding and most were at the recent NIH conference. Many were polite and thanked NIH for what they have done but have also voiced concerns that they need more funds. NIH can easily go back over previous applications that were rejected on spurious grounds (before ME/CFS was taken seriously) and approach the applicants with what would be needed to receive acceptance for the new FY2019 funding. This is the cause of the current plunging grant application rates. These researchers are trying to do what they can with no money and that does not include applying for grants they keep being rejected for. If you believe the information presented at your own conference then its plainly obvious these are not bad faith players.

Ending the routine rejection and funding the researchers with clear research objectives will help lead to a treatment and even a cure for ME/CFS in our lifetimes.

All the above mentioned in funding Open Medicine Foundation and Simmeron Research plus.....Support clinical trials that make sense such as Nancy Klimas's model-based approach to ME/CFS. This trial is not only innovative, but it opens a entirely new approach to finding treatments for diseases. The NIH should fund Klimas, not because of ME/CFS, but in order to assess the effectiveness of her novel model-based methodology for finding treatments for disease. (Isn't the NIH committed to being a leader in innovation?)

Cortene also presents a new drug, a novel hypothesis for ME/CFS, and now they have data. Why wouldn't the NIH be interested in supporting at least some funding for a trial like that?

Concerted campaigns to rectify the stigma in the medical and scientific communities about ME as well as campaign to bait interest in ME

At the April 2019 NIH conference Betsy Keller said 30 years ago it was already known that PwME had abnormal physiological response to exercise. And yet many clinicians, insurers, researchers still do not understand that ME is a physiological illness in which the usual guidelines for exertion do NOT apply and in fact can be quite harmful. And yet, after all these years, patients must repeatedly counter the (biopsychosocial) BPSers who contend that the hardware -read physiological - disease that we have can be fixed with a software - read CBT- upgrade. This unfairly burdens a very disabled population with exertion and stress that many cannot tolerate. One result is that patients forego

encounters with healthcare professionals to try to minimize stress and exertion. This unfair burden must be addressed. To do so a FIRM message, endorsed at the highest levels (heads of HHS, NIH, CDC, Surgeon General, etc) about the physiological nature of this disease (and the adverse impact of exertion beyond a patient's limits) MUST be widely and repeatedly disseminated to all healthcare professionals, medical societies, healthcare education programs, (etc) as well as publicly disseminated. NIH should drive this effort across agencies. Doing so would demonstrate leadership and commitment regarding ME and further strengthen relations with stakeholders (patients, advocates, researchers, clinicians, etc).

Note - see also the MEAction submission:

Committed funding

More CRCs

Encourage and support CRC education, clinician training, outreach

Multiple, multi-year ME specific RFAs

- More funding

- Stronger health economics evaluations - how many people are sick and what is the cost? Are current methods for assessing cost appropriate e.g. EQ-5D? Other disease e.g. Asthma, have created disease specific instrument that can be mapped to EQ-5D for a more accurate evaluation. Recommend this is done for MECFS and use novel digital/remote outreach methods to run large scale validation/mapping studies.

- More collaboration with pharma on very early stage exploratory hypotheses - what is stopping them from getting engaged?

- Engagement with the start-up ecosystem to leverage most advance tech/science. Start-up funding, events, partnerships etc.

- Raise awareness - fostering engagement with celebrity foundations can make a huge difference in public awareness, as seen with the Michael J Fox Foundation for Parkinson's research (whom NIH collaborates with).

MEICC criteria

Don't discount functional medicine, functional medicine providers, and naturopathic doctors, as well as insitutions which are forward thinking in mitochondrial medicine and systems biology. Stovepipes in medicine will not solve this disease, which is complex and multisystemic. Medical instututions are vastly ignorant, and "business as usual" will not suffice. It is going to take extraordinary effort, and commitment to leapfrogging thinking and treatments to begin to tackle this extraordinary crisis.

Thank you.

Funding!!!
The web site www.me-ireland.com outlines these approaches
Well, on a personal note, maybe if you could help me get better, I could help too. I'm offering a lot of ideas without offering to do any actual work. I've been able to get things into my brain but not much out, and am completely disabled with ME/CFS. I was a project manager at the beginning of an NIH funded national project (NCIBI) when I suddenly got sick ~12, 13, more years ago? Can't remember. Treatments I learned at your ME/CFS conference have let me organize my thoughts and write more than a paragraph or two. I haven't been able to write more than that for about ten years. I just can't believe I am doing this! Gleeeee!!!! But communicating with people is hard, I easily slip into PEM with any overexertion, and I generally don't want to talk to anyone but family or close friends because of this. I am housebound, and just a couple flares away from bedbound. My nightmare is people get interested but attach my name to it, and people, random and from my professional past, start calling out of the blue. I'm going to have to not answer any calls like that and I'm going to feel really bad about it, because I like and miss those people. Although I exercised myself into being completely housebound, I saved myself from dying from ME/CFS by following the age-old medical advice: Patient: Doctor, Doctor it hurts when I do this! Doctor: Well don't do that! I'm not sure there was a point to that joke. Thank You NIH! for applying ACTUAL SCIENCE to ME/CFS.
-See note about the National Database for Autism Research above -Funding for medical historians or investigators to help write honest and critical history of outbreaks. A history of the Incline Village outbreak could be a great PhD dissertation, for example. -Mentioning ME/CFS in announcements for non-MECFS-specific (but related) grant announcements, for example in comorbid conditions like Ehler-Danlos, endometriosis, neuropathic pain
Completely quell the psychology brigade who refuse to lose face over their grave mistakes.
For more information see RFI: Soliciting Input for New Research Strategies for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Notice Number: NOT-NS-16-024 Dated June 22, 2016. **[…]**

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The most important outcome to patients is to be in a positive spiral, a virtuous circle, rather than stuck in a downward spiraling vicious circle. Patients are thrown under the bus a lot by their families, disability services and medical providers. Sometimes they figure out how to help themselves, but most often their lives are very, very difficult. The greatest need will vary by patient. The research exists because patients are suffering, and we do not have many good answers for them. I believe the mission of research for ME/CFS is to improve the lives of the patients. That may require more than just biomedical research focused on solving the disease. We need to change the ME/CFS message received by caregivers, family, friends, employers, government agencies, media, and society in general. A systems approach suggests that sometimes you have to move a remote lever that seems secondary, to change the complex outcomes somewhere else. I believe this is the case for improving the overall field of ME/CFS research. We need to study more than the biology. For example, studying the epidemiology, as I mentioned above, might be a key to changing the game. Bringing ME/CFS to the attention of the larger Systems Biology research community also might be very important. This might include creating a network of allied research organizations. Additionally, this could include creating a publicity network that includes non-research ME/CFS stakeholders, a network that links together all the players in the social messages from and about the ME/CFS community. This could help patients receive better support from family and all the other players in their lives, beyond just the medical. And with better stabilized patients there is a better chance at competent research. We need to support the entire spectrum of interested parties, through providing information to non-researchers, well thought-out grant offerings for researchers, and find ways to encourage media players to help change the reputation of this serious condition. These types of change will circle back and translate into better support for ME/CFS research.
I may be in big trouble next time I see her because I know she is already spread too thin, but I can't close without noting that Dr. Irma Rey who shares the clinic with Dr. Nancy Klimas is a massive talent in her own right. She is academically brilliant, but also incredibly wise and very, very people-smart. She was by far the best fit for my trauma-specific ME, and I thank my stars every day for her and for […] Health Rising blog richly deserves a Pulitzer. I would be a lost life, past salvage by now, without them. END NOTE: I withheld active links to referenced analogs from this submission, for fear the online form might not accommodate? I would be pleased to provide the links, or any further information required, via e-mail.
Surveys should also seek to ascertain whether multiple cumulative infections, exposures, or injuries may be complicit in either initiating ME or affecting its severity. If this is indeed a maladaptive host response disease, allostatic load possibilities should be explored. Prospective studies would also be enabled by trigger tracking. Both enhanced scientific understanding and public health considerations mandate creation of a registry that – at a minimum – identifies the geographic residence and occupational exposure history of the patient. Better recognition of the illness in its complex form will also drastically reduce the cost and suffering burden of patients who are now kicked from specialist to specialist, overtested and improperly medicated for other conditions. For individuals who experience sudden onset following a flu-like

infection and then demonstrate the extensive highly-eccentric symptom clusters well described by the CCC and ICC, diagnosis could be readily made by any knowledgeable physician.

From a public health point of view, this raises the possibility of arresting – and even reversing – the disease process at the prodromal stage, when fewer symptoms may be present. Again, this mandates substantially improved recognition on the part of medical professionals of the precipitating factors and red flag symptoms at the very early stage of the disorder.

Listen the patient, listen, take us for many days consecutively please, not 20 minutes!