Identifying related scientific areas that may be relevant to ME/CFS and strategies for establishing collaborations with experts in those areas to help advance ME/CFS research
Collaborate with researchers in the field of cancer, MS, ALS, Parkinson's and other illness that cause fatigue.
Similarity to MS - and other autoimmune illnesses - in terms of response to treatment like LDN, hyperbaric oxygen etc.
Look at overlapping symptoms. Ehlers-Danlos Syndrome, Crohn's, disautonomia, POTS, endometriosis, autism, ADHD, Chiari malformation, CCI, AAI all have overlapping symptoms with ME. Open up collaboration with researchers in these areas.
Ditto
See above: A connected database so researchers and clinicians can access known successes and failures for both diagnosis, ongoing treatments, and biomarker assays. An annual ME/CFS NIH conference like the one in April 2019
Exercise physiology,.
Brain Injury https://www.nightingale.ca/our-founder
Overtaining syndrome appears to be a similar condition, so it may be worthwhile collaborating with researchers such as Tim Noakes, who has done research into central fatigue and overtraining.
Listed above
GI - Digestive issues causing the lack of ability to keep retroviruses in check. Neurology - BDNF gene
HIV, PANS, Lyme, Fibro HIV Cure Researchers (i.e. Deeks, etc)

Neurology. Infectious Disease. Cardiology(POTS). Possibly Hematology and Rheumatology.
GENETICS! Collaborate with EDS, dysautonomia, lipedema, and endometriosis experts! Please! Collaborate with researchers where onset is in puberty too like Type 1 diabetes!
Unknown
Dentistry agriculture physiotherapy (why are there no tests that can be done by these body experts? sure they could be useful in the testing and diagnosing of the condition, because its all about how the body is moving, able to move, not able to do things, can be measured by these experts and yet nothing is being donw in this field as far as I know, oncology infectious disease transplant clinics MS, Parkinson, lupus OBGYN Investigate the repression of certain medical tests that are ignored not many people get tested for, for example: 1. iron overload, Hemochromotosis, many people suffering from diabetes could be cured simply by doing blood letting because Hemo can cause diabetes 2. asthma is said by some researchers to be linked to mycoplasma pneumonia, yet when someone has asthma, there are no further investigations, what is the cause. During my search for a cure of cfs, I found a cure for my asthma, with taking very strong antibiotics.
MS, Parkinson's, autism, other neurological diseases Autoimmune diseases Dysautonomia

Ehlors Danos Syndrome
Stop going round in circles, wasting time & money while patients are suffering & dying unnecessarily. Instead, fund long term weekly acupuncture & herbs available in home for patients who are willing to try it & be studied. Patients ARE the best experts on their own bodies & this "mystery" disease that is as old as time.
Biobancos de muestras
Neurology - many neurologists are ignorant and dismissive about ME/CFS even though it is classified as a neurological disease. Educating neurologists could encourage them to bring their expertise to this field, especially regarding the autonomic nervous system disregulation, sensory and cognitive symptoms. Immunology Virology - many patients become unwell following enterovirus infection. We need the expertise of virologists and immunologists to understand how this triggers the disease. Cardiovascular Exercise physiology Need collaboration from all of these disciplines. The best way to get people involved is to educate them, help them get to conferences to meet fellow researchers in the field, and support them with grant applications and access to decent research funding (making them aware that this is available and you are keen to fund a lot more research on this field so they are encouraged to apply).
-Communicating across disciplines various aspects of initial research findings related to these diseases -such as communication from researchers involved in Primary Biliary Cholangitis (what is similar and different between these 2 diseases?) -Pulling in researchers who are expert in mitochondrial diseases, cellular metabolic problems
You won't even fund Ron Davis' Open Medicine foundation with enough funds to actually accomplish anything.
Reach out directly to the loudest voices in those related, possibly relevant areas. Think outside the box. Approach the big foundations and expose ME/CFS as a viable and worthy cause. For too long this has been the role of patients and their small group of advocates. If government agencies were to do the same - there is power in your esteemed persuasion.
This is beyond my ability to answer.

Dysautonomia, Lyme and other tick borne infections, Autism, Alzheimer's, Traumatic Brain Injury, Gulf War Illness, PTSD, Autoimmune Diseases. Multiple Chemical Sensitivity.

Create a new CFSAC type Commitee with experts from all the relevant fields.

Mast Cell disorder specialists and Hematologists who can correctly diagnose the patient subset who develops this devastating underlying comorbidity

Neurogastroenterologists who can correctly diagnosis and treat the dysmotility we experience as a cormorbidity

Neuroinflammation experts and migraine experts who can look for inflammation in our brains and invent a targeted treatment so we can decrease our pain and improve our damaged cognitive abilities.

Cutaneous disease experts of rare skin diseases to properly diagnose our strange circular rashes, hives, burning skin sensations, blood pooling, etc. For me, skin manifestations were one of my first symptoms. Dermatologists had no clue what they were seeing and did not send me anywhere useful. It was a dead end for me.

Small fiber poly Neuropathy experts who can screen us for neuropathy which is an underlying condition many of us develop as we get worse

Autonomic disease experts who can check for Orthostatic intolerance, brain inflammation, POTS, and cognitive issues, temperature regulation issues, neuropathy issues etc.

Connective tissue disease experts and rheumatologist because this is a huge factor that we don't understand and effects us in the joints, skin, skeleton, dura, tendons, etc.

CSF Leak doctors who understand the neurological and genetic components of MECFS, this is a comorbidity

Blood flow experts someone needs to study our blood systems veins, hearts, micro circulatory system, etc intracranial hyper and hypotension, POTS, OI, blood pooling, headaches, structural issues, bloid erasure issues, exercise intolerance, post exertions malaise. Tachycardia etc.

Immune system experts needed we still dont understand if this is a hyper or hypo immune state, many of us got sick after a major assault on bodies with infections

Lyme disease experts because everyone who has this disease questions whether it was a tick or virus or bacterial infection that caused this

Mold experts. This is a huge one that is always overlooked. I got sick because of mold. I had a nasal turbo ate surgery and had to move from my moldy apartment because I could not breathe in there and had 1+ year of repeated infections and now I have chronic fatigue and mastcell activation that won't go away even though I moved out. I believe this assault on my immune system activated these diseases. There is a very obvious connect there that long term exposure to mold pathogens leads to chronic illness.

Endocrinologists are needed. There is a thyroid component for many of us as well as problems with metabolism and Energy production at a cellular level. We do not have enough energy to work, play and have a life. If we store up energy we can do things but we always crash after and spend days, weeks, months recuperating. It's extremely difficult to understand how to pace ourselves. Our bodies do not give us a sign that we are about to crash. We would need tests or monitors for this
Look to the International Primer and Ron Davis and Jarred Younger. THeya re great examples of bringing in researchers from other fields
Sport and exercise research Research into autonomic nervous system Gut microbiota research
- common comorbidities (POTS, Fibromyalgia, EDS ...) - brain inflammation - viral measuring in the cells - lymphatic system - endogenous retro viruses
Yes. Several labs, doctors, Researchers are working to cure MECFS across the world. NINDS to collaborate with Dr. Ron Davis of Standford. Need for multi-focal studies especially for post exertion malaise.
Invest in ME Research (UK charity) - follow their model and engage with them on research Focus on the most severely ill Fund more research for biomarkers and biomedical diagnostic tests
Annual Meetings sponsored by NIH on Chronic Fatigue bringing researchers together.
CREATE A WELL FUNDED TRUE 'HOME' FOR US WITHIN HHS THAT INCLUDES ALL SPECIALTIES.
Work with the exercise physiologists and other experts familiar with over training syndrome as the physiological abnormalites seen in ME/CFS parallel over training syndrome.

If there is a genetic component, genome sequencing and DNA research may prove to be very relevant.
Talk to and collaborate with the exercise physiologists and persons interested in exercise intolerance , as it is the cardinal symptom of the disease . If comparing to other diseases compare the key symptoms of ME/CFS ie the exertion intolerance, orthostatic intolerance, sleep disruptions, cognitive impairment. Move away from the subjective "fatigue" measures as patients find it much easier to use other markers eg sore throat....or heart rate data. If patients find it hard to quantify fatigue how can it be a reliable "measure".
Autism has similarities w M.E. Help expedite Rob Naviaux UCSD Suramin trial that has been roadblocked by NIH, FDA for years. Very low risk, low cost drug, approved in Africa, 100 years old, but cannot get this in USA legally
Look for similarities between ms, fibromyalgia and lupus. Look for common triggers, lab results and treatments.
Paul Cheney of Asheville, NC has 30+ years in the field as a pioneer in it. He is now retired as a clinicsl practitioner with severe heart disease. Make it a priority to interview him in detail regarding his treatments, many forward-thinking, regarding the over 5000 patients he treated. This should be soon because of his heart condition and age.
This is above my pay grade, as are most of these questions.
Develop “assigned/paid” liaisons with leaders or even patient advocates in various related scientific areas who schedule events, coordinate communication, set up social media sights etc.
The symptoms of people who have chronic tick-borne illnesses, whether untreated, partially treated or untreated, can fulfill all the criteria for CFS/ME. It would be great if there could be some collaboration to see if the controversial so-called post-Lyme syndrome is really CFS/ME or see howor if they may differ. Both groups of patients need help learning to manage their conditions in the short term and a cure in the long term.
There needs to be established markers researching the illness duration, such as: 1-3 yrs, 1-5 yrs, 1-10yrs, 10+ yrs to study what changes as the body deteriorates fighting this illness.
I know it is expensive but a wider database of blood samples and a computer program to find the same viruses or whatever in each them, a database of several thousand would be better than just a few hundred, as doing a study with just a few hundred will have to be repeated because of the low numbers, this would be more expensive but not having to repeat it in the long run would be cheaper. Taking into account each and everyone's symptoms. After hearing about the oxygen issues to muscles it pointed you in one of the right directions, ask everyone their symptoms, compare notes and find the common denominators.Computer spreadsheets can do this as well, entering the symptom that correlates closest to what is on the spreadsheet and then get the g-final numbers after this has been done for thousands not just hundreds.Work from home mothers, etc an do this. It is an untapped workforce. It is easy to train them to do it, train one person and have them train the others. So many

people want to work from home.Some patients can do it as well as they feel up to it, It is a huge undertaking but it will show you the best direction to go in on research, ask the patients, but use the workforce of work from home folks.
I have personally researched mitochondrial dysfunction and through trial and error am currently on lipid replacement therapy that is working to reduce the daily pain and fatigue. Molecular biologists and other experts in cellular science would be a great place to start.
No input on this point.
Immunological, molecular and microbiome studies and cross collaborations that could benefit ME and other diseases interested in studying the same targets.
ME/CFS affects almost every area in the body. All medical professionals should have enough education to include it in their thinking about diagnosis. So far, none of the doctors I have seen outside of those doing research are even aware of the illness.
-
There is an absence of research into sleep disorders in ME/CFS, which is odd given that unrefreshing sleep (early disease stage) and severe insomnia (late disease stage) are the only universal symptoms (along with post-exertion neuro-immune exhaustion). The severe insomnia in those with the disease for more than a few years is the symptom that causes the most suffering and, because it exacerbates all other symptoms, is the leading cause of patient suicide.
Neurology. They need education in this area.. GI doctor-education on the illness and the possible need for biopsies Infectious disease-they need to identify the pathogens, and need to be educated. Pathology-they can identify the pathogens involved....
Increased funding.
Infectious Disease, Cardiology, Neurology, Rheumatology, Endocrinology, Psychiatry, Psychology, Pediatrics, PT, OT to name some specialties that will help establish and benefit if collaboration is involved with these specialties.
There is definately neurological and gastrological impacts of ME. GOOD PLACE TO START.
Please list ME/CFS (along with all its other names) in all the NIH lists of diseases. There is no excuse for it not being listed.

Other neuro immune diseases like MS and Parkinsons
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)
/
See comments above.
ME/CFS patients are also treated with plasmapheresis by Dr. Straube, INUS Medical Centre, in Cham, Bavaria, Germany. Information about the treatment is available in English via: https://www.gesundheitsparkcham.de/treatment-procedure/
see above comments
-Communicating across disciplines various aspects of initial research findings related to these diseases -such as communication from researchers involved in Primary Biliary Cholangitis (what is similar and different between these 2 diseases?) -Pulling in researchers who are expert in mitochondrial diseases and cellular metabolic problems
Immunology Cardiology Infectious diseases

I want to advocate looking for common links in patients' health history, as mentioned above.
Mold and toxins. A LOT of us got this disease after getting vaccines or environmental toxins! Why isn't this being looked into???? Because the government doesn't want to pay 2.5 MILLION people disability????
For a long time we believed ME/CFS was connected to depression. Even if it's not (which I don't believe the research supports anymore) we can still compare notes and see where the differences lie. What other diseases also include a fatigue aspect? Note the differences in those as well and isolate what makes ME/CFS unique to them.
Biomonitoring. Previous literature suggests lots of noninvasive potential tests that could be run constantly in daily life to reduce likely hood of experiencing severe PEM. Flicker fusion frequency - a simple 'is this flickering yes/no' test on a pair of goggles, performed like audio tests with variable frequencies and detect/no detect. Cerebral perfusion changes. May ultrasonic or galvanic changes be useful. Balance changes on standing - variation of jitter and frequency response are very indicative of neural performance. Perhaps even something simpler, n-back, or reaction time tests may be useful for individuals to monitor their condition.
Produce a Cross Institute Multidisciplinary 5 Year Fatigue Initiative including RFA's and Conferences to create interest and facilitate collaboration Emphasize how fatigue is a core symptom in many diseases, how little is known about it, the great need to learn more about it, and how ME/CFS - one of the most functionally disabling diseases on the planet - provides a unique opportunity to unlock much that is unknown about fatigue. Multiple sclerosis, POTS, Ehlers Danlos Syndrome, MCAS, rheumatoid arthitis, primary biliary cirrhosis, Parkinson's disease, migraine, overtraining syndrome, mitochondrial diseases, depression/anxiety
N/A
Produce a Cross Institute Multidisciplinary multiyear Fatigue Initiative including RFA's and Conferences to create interest and facilitate collaboration Emphasize how fatigue is a core symptom in many diseases, how little is known about it, the great need to learn more about it, and how ME/CFS -one of the most functionally disabling diseases on the

planet -provides a unique opportunity to unlock much that is unknown about fatigue. At a minimum fund a four-five day Fatigue Conference to bring researchers from across the spectrum to learn from and interact with and form collaborations with each other. Give VIcky Whittemore more funding and assistance to carry out her job
MS, once called hysterical paralysis, would be a good model. There should be recognition that pwME are at a point MS was not that long ago.
Work with other countries and include their studies and knowledge
MS
My most disabling symptom is orthostatic intolerance. I would like to see more investment in that area.-Both in understanding its source and its treatment
Make clear to patients, doctors, medical schools, legislators and insurance companies that the PACE trial was fraudulent on several grounds. Call for retraction of their published work.
There seems to be a high level of co-morbidity between CFS and disease like fibromyalgia and migraine with aura, for which studies have also demonstrated inflammation in the brain.
Again, it seems that there should be one underlying issue that can be related to ME/CFS and other contingent (?) illnesses like Lyme, fibromyalgia, Ehlers-Danlo's Syndrome, POTS, PEM, etc. Seems to me that Ramsay's study found something that could account for or explain, for instance, POTS, PEM, etc.
viruses, HHV6, Immunology, Neurology, oxygen utilization, metabolome, detoxification pathways, cell danger response, epigenetics, and autoimmunity.
As before, I believe neurology and neurology research could prove valuable to ME/CFS.
As above
Autoimmune, vascular and impact on those in over training in sports

Emphasize how fatigue is a core symptom in many diseases, how little is known about it, the great need to learn more about it, and how ME/CFS -one of the most functionally disabling diseases on the planet -provides a unique opportunity to unlock much that is unknown about fatigue.
autonomic system researchers, immunology researchers, etc. ASK Jared Younger for input.
Encourage researchers to publish in more general and prestigious journals such as Science, Nature and PNAS, and encourage these journals to publish ME/CFS research, particularly since such research will surely shed a light on other fatiguing and neuro-immune conditions. Understanding ME/CFS should have wide applicability to other poorly understood, chronic illnesses.
(See above) possibly partner with other similar brain health illnesses / research (at least for a portion of the effort / budget) Tag a small portion of the budget for identifying cross / co- research partners.
Any areas that investigate post exertional mailaise, postural tachycardia, unrelenting fatigue, brain inflammation, chemical exposure/damage to the body from those, other cultures with fewer cases, mitochondria, autism.
Time frame delay for seeing the top specialists working on ME. Some people shouldn't have to wait years for an appointment. it may be too late.
Comorbidities. We need to be asking more detailed questions! For example, a lot of people with CFS/ME develop new and worsening allergies to environmental allergens and foods, yet this is something that seems overlooked in the literature. If we are going to track down similarities between patients, we need thorough studies of said patients and everything that affects them.
Immunology and inflammation two two big drivers of this I believe. I also think a lot of this is related to endocrine disrupting hormones (pesticides, plastics, etc) in the environment. I think CFS sufferers are the human equivalent of the canary in the coal mine.
not sure, but this is also way too much for a brain fogged, exhausted ME patient to try to answer all in one sitting.....I really appreciate that you want our input, but it needs to be in such a way that we can answer some and then save & return to it.....I've already used up way more energy & brain power than I have for most of the week in answering the questions that I already did
There are so many. Seems to share symptoms with Parkinsons, MS, Fibromyalgia, Migraine, sepsis, shock. Discoveries in RBC deformability, neuroinflammation, metabolomics, genetics, many, many others.
Chemical Sensitivities, Electrical Sensitivities, TILT (Toxic Induced Loss of Tolerange).

I think that ME/CFS research often needs to widen the net when it looks at "fatigue" and PEM. We get findings of things like increased gut permeability, bacteria translocation into the bloodstream, evidence of mitochondrial disturbance, high oxidative / nitrosative stress, etc but unless you compare it to other illness groups, how significant or unique are these findings in terms of the pathology of the illness? Global understanding of the mechanisms of "fatigue", given that, alongside pain, it is possibly the most prevalent and debilitating symptom in many illnesses, still seems to be in its infancy. Over the years I have noted many groups that seem to have significant symptom cross-over with ME/CFS, including traumatic brain injury, altitude sickness, and patients undergoing chemotherapy. What is going on with the immune systems, guts and metabolomics of these groups compared to ME/CFS? What is the same and what is different or unique about ME/CFS?
Since there are differing opinions on what kind of disease ME is, there would have to be many research fields involved. Study of autoimmune disease, immune system, neurological disease (brain, small fiber, vagus nerve, spinal cord), cardiac disease, inflammation (body and brain), muscle, and exercise physiology. Perhaps a team of people knowledgeable in ME research could comb published material on relevant topics to ME and act as a “match maker” between researchers. It would be good if funds were made available for researchers to travel between labs to witness how others are doing relevant research.
Vaccinations, and the effect of food allergies, diabetes on the rise, chronic illess such as Lot Gerhigs, Parkinsonism, Autism, etc....these have been proven to be treat me. Where is the research from your organizations? Why don't you loosen the restrictions on the Insurance companies by switching out the IDSA for ILADS who really know how to treat these disease? Allow us to get healing without loosing our homes. Make it easier to get disability. Take down the roadblocks. Please.
Researchers all seem to making progress on abnormalities, but none of it has filtered down to the patients.
Finding the reasoning behind why some of us get muscle spasms which cannot be treated with any medicine, pain and brain fog management.
Genetics (family history) Metabolomics (energy generation, ATP, mitochondrial function) Gut microbiome (explore changes to stool flora and fauna as a diagnostic and treatment option) Immunology (autoimmune, lingering reactions to viruses like EBV, glandular fever) Virology (to see if there is a lingering, ongoing viral infection with flare-ups or post-viral symptoms)
See "overcoming challenges" questions
Organise an annual conference for all related diseases e.g. ME/CFS, MS, autoimmunity; neuroimmune illnesses, and attract all the top researchers and clinicians from all these fields to share ideas.

Be open to the field of functional medicine which, I feel, has a lot to offer*. Consider asking Dr Dale Bredesen (Alzheimer's); Dr David Perlmutter (neuro); Dr Terry Wahls (MS); Dr Amy Myers (Autoimmunity) to speak and collaborate with ME/CFS researchers and physicians. I think Dr Bredesen's programmatic / multi-pronged approach to AD could easily translate to ME/CFS and I'd love to see how he might approach ME/CFS. * I'm also a doctor (although unfortunately, I've not been able to work for many years due to ME/CFS) but have seen some truly significant changes in people's health after advising them to follow a functional medicine approach, often benefits that would defy conventional medical thinking. It's an approach that, with my western medical training (Cambridge, UK), I would previously have been very sceptical of but the outcomes are often so rapid and significant that I feel that this approach can add significantly to all fields of medicine, including ME/CFS. Consider a conference aimed at biotech / engineering researchers (perhaps at somewhere like MIT) to bring the field of ME/CFS to people who may be able to contribute significantly, but probably don't even know about the illness (for example, it's amazing to see what Dr Robert Phair's engineering approach has brought to the field of ME/CFS and I'm sure many others with similar academic backgrounds to Dr Phair could do similarly). Consider involving the Santa Fe Institute to allow for some big-picture thinking of how to approach a complex, multisystem illness like ME/CS.
The more researcher are aware of what's happening in the field, the more interest there will be. We need ME/CFS to be embraced by the entire medical community, not just a distinguished few.
Bring together physicians that specialize in co-morbid diseases such as migraines, fibromyalgia, and IBS with CFS researchers to see if they can find any combined approach that CFS patients can send their doctors to.
Peer to peer conferences
Fibromyalgia
I am not a research scientist, and only have a vague grasp of the very wide scope of ME/CFS, but my understanding is that it may be helpful to connect with experts on mononucleosis, /Epstein-Barr virus, autoimmune dysfunction, stress-induced biosystem failures, mitochondrial (dis)function, sleep, nutrition, and (gut) microbiome developments, interactions and failures.
AAEM: https://www.aaemonline.org/positionpapers.php IAOMT: https://iaomt.org/resources/fluoride-facts/
- immunology, autonomic dysfunction, cellular energy metabolomics, DNA methylation, intracellular communications (vesicles), chronic viral infections, inflammatory dysfunction, microRNA, exercise intolerance

- highlight recent ME/CFS work and the researchers doing the work in targeted publications. - offer significant grant money in related fields - advertise ME/CFS conferences in targeted journals
See above comments re: expertise from Dr Paul Cheney and others already working in ME/CFS as long-time clinicians. Dr Cheney in particular is always exploring adjunct areas of medicine and science, and how they may be applied to benefit us.
Deep learning: A programming contest should be held at universities and colleges to develope a program which, given a swath of open source patient information (from cytokines, to DNA, to brain inflammation maps) delivers novel insights by pattern recognition. Open source data should include not just biometric but environmental information if possible. No need to worry if control in type of data point are not maintained from sample set to sample set, deep learning should be able to identify some correlations despite this. A small cash prize along with a short letter of recommendation from some prominent researcher could be given to any winner. The 'hackathon' should be advertised to students taking relevant classes.
Dr. Belpomme (France); Dr. Beatrice Golomb (CA); Dr. Martin Pall ... all electomagnetic, non-ionizing radiation research and some into electromagnetic sensitivity... provide funding or support for research collaboration
huh?
Obviously there seem overlap with inflammatory and immune conditions, as well as FM etc.
You must look at the effect of wireless on energy production / health. You must. You can have internet that is wired and totally free of effects on one's health and esp energy production, a key variable in CFS. Radiofrequency Radiation Engineers would be needed, also probably Electrical Engineers like William Bathgate, Michigan who understands these effects on health (RF is not the only issue, the smart meters put conducted frequencies on the household wiring , the effect of that on CFS should also be explored.) CLEVELAND CLINIC CENTER FOR FUNCTIONAL MEDICINE - involve Mark Hyman's team!!!! They are the best ever at this. I cannot say enough about what they did for me. The before photo of my sitting, holding my daughter age 4 because I was too fatigued to stand at Christmas, side by side with the photo of me skiing with her a few years later sums it all up. There is so much home for people with CFS, and Cleveland's CFM has got the answers.

Dieticians trained in Functional Medicine, especially the Wahls protocol or mitochondrial diets
MD's in the functional medicine field should be folded into the research partnerships. Functional MD's were treating patients with current treatments for me CFS 10 years before it became standard medical practice. They are ahead of their time and their information should be assessed.
Readily encourage collaborations between neurology, cardiology, immunology, endocrinology. Within the NIH itself, have these different houses work together on research for ME/CFS, and maybe have a friendly competition with a bonus on who can discover the greatest impact of ME/CFS in their field or which system is where the problems with ME/CFS originate.
Just as cancer researchers became interested in HIV research during my career. Today, HIV researchers may be drawn to ME as the HIV response has become more refined. There needs to be cross-specialty investigation. Again, the conference provided interesting directions to pursue. The energy problems and neuroinflammation will attract investigators specializing in a variety of specialties and they will benefit from the cross fertilization. Just as ME patients currently seek care from infectious disease specialists, pulmonologists, immunologists, gastroenterologists, and neurologists, researchers addressing ME have to extend their inquiry beyond their circumscribed specialties.
Comparison of ME to the similar neurological disease MS would be useful. The well-documented epidemic occurrences of ME requires an explanation. The related pathogens, especially enteroviruses, need to be intensively researched using infectious disease expertise.
Scientific Areas: Microbiome Metabolomics Exercise Intolerance Neuroimaging Neuroinflammation Autonomic Nervous System Neurovirology Neuroendocrine Hematology Immunology Rheumatology Nutrition Emergency Medicine Integrative Medicine Fatigue, cancer fatigue

Sleep dysfunction Orthostatic, vascular dysfunction Diseases: Mitochondrial disorders Connective Tissue Diseases (EDS, etc.) Small-fiber neuropathy Fibromyalgia Dysautonomia (POTS, NMH, etc.) Mast Cell Activation Syndrome Neurologic trauma Neuroinfections, viral encephalitis Neurostructural disorders (spinal stenosis, CII, cranial hypertension, Chiari malformation, CFS leak, cranial hypoperfusion, etc.) Neurodegenerative disorders (Parkinson's, Alzheimer's, etc.) Neurologic autoimmunities (MS, MG, etc.) Humoral autoimmunities (Hashimoto's thyroiditis, Sjogren's, SLE, etc.) Autoinflammatory disorders (MCAS, PFAPA/FMF, APS, sarcoidosis, etc.) Immunodeficiencies (hypogammaglobulinemia, etc.) Endocrine disorders (hypothyroidism, pituitary tumor, Hashimoto's, etc.) Brain, pituitary tumors Migraine
Adapt and use ICC definition.
The only area relevant to 'ME/CFS' is quackery. Scientific areas relevant to ME research are: Polio research. ME is a type of non-paralytic polio.

EBV research. EBV breaks down the blood-brain barrier and weakens the immune system, setting the stage for a devastating enteroviral infection of the brain.
As stated above in previous questions, this disease needs to be researched and explored from so many different standpoints: neurologically, rheumatically, metabolically, via virology and infectious diseases, through endocrinology, and through cardiology, and etc. Researchers will need to be given collaborative access within MANY of the NIH institutes as ME/CFS is systemic and affects nearly every organ. This will also go more smoothly if the experts in other fields are already educated about the true nature of ME/CFS. First though, what is needed is the funding, resources, and ability to test each ME/CFS researcher's theories on a grand enough scale. It is unlikely that just one factor is singularly responsible for disease onset let alone persistent mechanism, therefore it must be necessary for all ME/CFS researchers with hypotheses and data stemming from any sub-field or different field of expertise, to bring their individual puzzle pieces together. These ME/CFS researchers need the resources and support to each present their actually adequate research to one another with conclusive data that sparks even newer ideas and perhaps novel treatments. This will naturally likely require the expertise and knowledge of those within the 27 Institutes to help extrapolate and advance a theory or connection. It might even lead to an idea that an already FDA approved drug used in an entirely different field might have benefits for CFS/ME patients off label. The NIH should actually facilitate connections between those within the ME/CFS working group and specific researchers who are experts in their other fields. The NIH should identify relevant research being conducted by others in the other institutes with other expertise that are even remotely relevant or related to ongoing ME/CFS research and facilitate meetings and collaborations.
Establish a center of excellence for Fatiguing Illnesses, including ME/CFS & Cancer Related Fatigue. Scientists can investigate and share similarities and differences between illnesses that help uncover the causes of severe fatigue.
AIDS research
Micro -RNA, and exosomes, need to work with the leading research groups. E.g. in the case of exosomes, what are the parent cells, are these exosomes transmitted across the blood/brain barrier? Initiating infection; evidence of previous infections and are they the cause of ME. Is there any evidence of persistence of these agents i.e. causing ME (e.g. Prusty). Experts in other areas - researchers in infection (Lipkin/Department of Defence), blood brain barrier (Alzheimer's), exosomes (diabetes, Alzheimer's, multiple sclerosis and type 2 diabetes).
Current research experts are stuck on the same research over and over and over with no results. The new research studies have been remarkable in making headway. Kudos!
Important for the reasons discussed above.

There are a number of illnesses that place individuals at increased risk of ME/CFS and which are frequently comorbid with ME/CFS. Instead of excluding individuals with these illnesses from ME/CFS studies, they could be included as comparator groups to identify potential commonalities that may speak to the etiology of the illness in subgroups. The data generated would be valuable to multiple research communities, and partnerships between supporting organizations would benefit all with the common goal of increasing awareness and support of these “invisible” illnesses.

As ME/CFS is systemic and there may be many factors responsible for the disease, we must have collaboration of research in different fields, including virology, neurology, endocrinology, etc... the NIH should set up and sponsor this collaboration between relevant researchers in these fields to put all the pieces together to identify treatments. Only the NIH would know of relevant research to be able to facilitate the connections between ME/CFS researchers and experts in other fields whose research may be key to moving the needle forward in ME/CFS research.

See above.

INTERDISCIPLINARY COLLABORATIVE

COLLABORATIVE RESEARCH CENTERS

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!!!

Areas that may or may not be related to ME/CFS (and discovering if they are or not would be a big help):

1) exosomes

2) low-level brain inflammation (chronic microglial activation or priming)

3) prions

4) biofilms

5) mold reactions, especially sensitivities and reactions to low levels of mold

6) difficult to detect parasites, such as the West African Sleeping Sickness trypanosome

7) chemical exposures and/or allergies

1) Collaboration with the pharmaceutical industry.

2) Money for basic research aiming at fully understanding the disease mechanism in ME. 3) When ME is fully understood, we should explore if approved drugs for other diseases could be relevant for ME in order to make meds available to patients as fast as possible.
Thyroid Genetics because 4 generations are affected
-Provide travel funding specifically for NIH and NIH-funded researchers to make presentations at conferences in related fields, such as immunology, neurology, rheumatology, metabolomics, informatics, etc. -Provide travel grants for researchers in related fields to attend and present at the (hopefully annual) NIH conference on ME/CFS research.
Multiple Chemical Sensitivities. Genetics (e.g the P450 genetic mutations that affect the correct processing of meds in the body) Integrative Medicine Pharmacy
hematology immunology pulmonology cardiology oncology ion channels metabolism (energy production, acid/base balance, glycogen) cell signaling nephrology (acid/base balance, angiotensin-renin-aldosteron disruptions, electrolyte problems--maybe they can sort the cause of the low blood volume) genetics neurology (weak muscles, for instance, and comorbid migraine, and dysautonomia, and neuropathy, and pain generally) gastroenterology cell transport

Denuge fever (compensated shock) seems to have some similarities

I ALWAYS find people in POTS, Dysautonomia, and Fibromyalgia groups who have symptoms beyond their diagnosis who identify with the ICC once they have been shown the ICC questionnaire. The FIRST step must be to use the ICC as a screening tool before giving a CFS, ME/CFS, Fibro, or dysautonomia diagnosis. It's clear from talking with fellow patients that the doctors need educated on how to diagnosis.

By getting proper diagnosis, then we can properly collaborate with experts in those other diseases.

Talk to Nancy Klimas MD of the Institute for Neuro Immune Medicine at Nova Southeastern University in Florida. She has managed to piggyback ME/CFS research onto already funded GWI and Parkinson's research, because the ME/CFS research dollars are so scarce. But she's creative. Imagine what she could do with funding specifically allocated for ME/CFS. So she is very knowledgeable about related scientific areas related to ME/CFS, including Gulf War Illness and Parkinson's.

The typical siloed nature of medicine works against making progress in a multi-systemic disease. Collaboration across disciplines is the exception, rather than the norm. To make significant headways, it will be necessary to build resources that bridge disciplines and break down the usual walls of over-specialisation.

There is currently no medical specialty that takes ownership of the disease. This breaks the standard approach of GP referrals, when there is no one to refer to and GPs simply cannot have reliable expertise to handle such a complex disease.

This seems to be common with diseases that affect the immune system, a strong case for a new approach that bridges the various gaps that have accumulated, warranting a need for cross-disciplinary work that has not yet materialized. Perhaps a specialty of complex chronic diseases, especially those that defy the typical one-symptom requirement and the exceptional nature of fluctuating diseases, which all tend to suffer from anything from outright contempt to common misdiagnosis and delayed diagnoses.

A curious observation is that most ME/CFS patients show involvement of the immune system and have to avoid most foods due to intolerances. This may be secondary, but I believe it is worthwhile to draw in research from this area. I particularly suggest the following researchers due to their groundbreaking work:

* Detlef Schuppan from Mainz (Germany) and Stanford (US) has recently shown that certain proteins (ATI) in wheat activate the innate immune system via TLR4. He also works on detecting food intolerance directly in the digestive tract.

*Jonathan J Lyons from the NIH (US) has identified Hereditary Alpha-Tryptasemia as a new disease and works on mast cell disorders, which mediate intolerance reactions.

Collaborations with our “cousins” such as fibromyalgia, POTS, HSD/hEDS, dysautonomia

Currently there is an abundance of evidence pointing to a dysfunction of the central nervous system in ME/CFS. We believe future research needs to include research to identify solid objective findings in the neuraxis.

Much of the research to date has focussed on biochemical changes in patients with ME/ CFS (Morris G. et al. 2019, Nagy-Szakai D et al. 2018 & Naviaux RK. et al.2016,)

There has been little attention on bio-physical disturbance with the exception of Prof Peter Rowe and his team at Johns Hopkins, Baltimore (Rowe PC et al. 2014) and Dr Ray Perrin in the UK (Perrin et al 1998, Perrin 1993, 2010,2011,2013 & 2018). In 2005, Perrin published his doctoral thesis on the involvement of neuro-lymphatic pathways in the pathogenesis of ME/CFS. Perrin, who has continued this research for 14 years post-doctorally, hypothesized that autonomic dysfunction leads to retrograde neuro-lymphatic drainage via perivascular (Virchow-Robin) spaces. This leads to an increase in cytokine activity in the CNS and many other neurotoxins affecting primarily the hypothalamus and central autonomic control. The neurotoxic disturbance of different central neural pathways leads to the diverse symptomatology of this complex disorder. This leads to physical signs that have been shown to be significant as an aid to ME/CFS diagnosis (Hives L et al 2017). This alone could help the notoriously difficult and prolonged issue of diagnosis of ME/CFS based usually on exclusion. In this study an experienced NHS Physician was only able to identify 44% of the patients with ME/CFS from standard neurological and rheumatological clinical tests whilst observing illness behavior. However practitioners examining the physical signs discovered by Perrin scored an 86% accuracy in identifying ME/CFS.

The advice to physicians given by the international Association of CFS/ME states that the establishing the diagnosis of ME/CFS will usually give the patient much relief. (Friedberg F. et al 2014)Of course early diagnosis screening tools such as the physical signs can be then followed by early intervention with treatments such as Perrin Technique and advice on pacing and relaxation techniques. These 3 interventions were placed top of one of the largest national surveys of opinion among people with ME/CFS and their carers run by The ME Association of the UK in 2010. (Managing My ME. What people with ME/CFS and their carers want from the UK's health and social services. Me Association 2010)

In a study carried out at The University of Manchester, we examined possible differences in standard low intensity MRI scans in ME/ CFS compared with healthy controls. Changes in white matter, blood and CSF were analysed following a manual technique designed to aid neuro-lymphatic drainage. However at the time of the study (2001-2) we were not able to examine flow in perivascular spaces accurately. (Perrin, Embleton, Pentreath & Jackson 2010).

In 2017, an NIH sponsored research study led by Absinta & Ha (Absinta, Ha et al. 2017) along with researchers from the National Cancer Institute (NCI), using MRI scans discovered lymphatic vessels in the dura of the human brain.

As there are now some trained Perrin Technique practitioners in the USA, it is hoped that the NIH will consider supporting researcher education in this field by funding an exchange trip to visit colleauges at NCI. The aim is to share our experience.

In the longer term we aim to establish a collaboration between the researchers from the NCI and the University of Manchester with the sharing of scanning protocols to carry out the first joint

longitudinal study on a cohort of ME/CFS patients and healthy controls using the same protocol as documented in the Absinta et al study.

Prior and after an injection of gadolinium-based contrast agent, high-resolution MRI sequences will be collected and repeated in a cohort of healthy controls matched with a group ME/CFS patient some following a year course of treatment using the Perrin Technique protocol plus some ME/CFS patients not receiving the treatment. Any change in the amount of lymph drainage of the brain will be monitored and analysed

Comparing the scans of healthy subjects with ME /CFS patients and pre and post treatment, this radiological method could potentially demonstrate a disturbance in the normal lymphatic drainage in ME/CFS and if so would explain how interventions aimed at improving the lymphatic drainage of the CNS, such as The Perrin Technique, could help patients' symptoms. These symptoms include post exertional physical and cognitive fatigue, brain fog, autonomic disturbances such as neuromediated hypotension, temperature regulation, generalized myalgia, head neck and back pain, sleep disturbance and limbic function. (Perrin, Edwards and Hartley. 1998)

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MCAS, POTS, autonomic dysfunction, lymphatic system in our brain, mitochondrial research, discrimination research; PANS;

The best collaborations I have had resulted from my approaching others whom I know have a particular type of expertise, and those others becoming engaged in a joint project because I have presented an interesting question to them (or vice versa--sometimes people have approached me). Existing investigators could be ambassadors spreading interest in the disease to others who are ignorant about it--but only the existing investigators are funded themselves, and the potential collaborators could see RFAs to which they might apply.

Neurology, virology, immunology, genetics? It's difficult to say as it isn't yet known where or why these illnesses manifest in the body. I can say that it feels like it consumes your entire body from the inside out. It's in the brain, the nervous system, ligaments and tendons and skin, it affects vision and hearing, it breaks down immunity, it causes muscle deterioration, and on and on. It affects more body systems than not.

Related Areas

There are many related areas I think may be relevant to ME/CFS research. In particular:

Functional Medicine: Dr. Mark Hyman

https://www.ifm.org/

Adrenal Fatigue Syndrome: Dr. Michael Lam M.D., M.P.H., A.B.A.A.M.

https://www.drlam.com/about/

Migraine (a migraine medication I have recently started, Aimovig, has had some unexpected benefits on symptoms related to ME/CFS: weather sensitivity, nociceptive pain).

http://practicalneurology.com/2018/02/calcitonin-gene-related-peptide-monoclonal-antibodies/

Biotech is a very promising area: Biotime in Alameda, California. CEO Michael West, PhD successfully isolated therapeutic cloning "regenerative" gene.

https://www.biotimeinc.com/category/updatesfromtheceo/

Immunosenescence

Stem Cell Research

I think one of the most compelling ways to get scientists excited about researching ME/CFS is to present them with the true stories of how ME/CFS has impacted the lives of the people who live with it.

Beyond that, presenting them with the constellation of physiological processes that make up the disease would seem to me to be an exciting puzzle for any researcher to solve.

As a researcher, I suppose I would like to see what kind of logistical support I would have, in terms of previously established researchers in the field, funding sources, patient advocacy groups and other types of infrastructure organizations, as well as their past accomplishments and future plans.

1. Almost all ME/CFS patient suffer from at least one other medical comorbidity. Therefore, it makes sense to inform researchers studying those co-morbidities that ME/CFS patients provide another source of study participants for their work. Examples of common comorbidities include fibromyalgia, hypothyroidism, irritable bowel syndrome migraines, chronic sinusitis, mast cell activation syndrome, orthostatic intolerance, multiple chemical sensitivities (also known as idiopathic environmental intolerance), sleep apnea.

2. With the older findings by Dr. Susumu Tanaka and recent findings by Drs. Carmen Scheibenborgen/ Dr. Jonas Bergquist concerning presence of autoantibodies to muscarinic and adrenergic receptors in some ME/CFS patients, there should be an effort to reach out to scientists and clinicians working in the field of autoimmune neurology, which has been growing beyond multiple sclerosis, in the last few years. See:

https://nn.neurology.org/content/4/4/e373.short

Comparison studies of ME to HIV research, MS/EBV research, Autism Spectrum Disorders (ASD) research. And familial relation studies to ME and associated disorders such as fibromyalgia, immune disorders/cancers, autoimmune disease prevalence and food allergies/intolerance.

Study cardiac abnormalities, central nervous system issues, reactivated viruses and opportunistic infections which are likely a downstream effects of B-cell and T-cell abnormalities.

For example follow up on 1992 research: https://www.nytimes.com/1992/07/22/world/doctors-find-aids-like-disease-without-hiv-virus-is-growing.html?smid=tw-share

Dr Klimas has combined much of her ME/CFS work with her Gulf War Illness research. There are many similarities and many differences as she has noted in her NIH talk. Part of this is because of the similarities and part of it is because she cannot get funds to do ME/CFS research any other way.

Many of the other researchers had started in other areas before coming to ME/CFS research, from immunology to mitochondria to DNA expertise to oncology.

As we don't yet know the disease mechanism of ME/CFS it is more difficult to understand what are the most related scientific areas but this will become self solving once more research is completed and published.

OMF has done the most in this area by partnering with researchers from many disciplines who have decided to move into ME/CFS. Also Euromene is putting together researchers and ideas in ME research.

(need to rest now)

Produce a Cross Institute Multidisciplinary multiyear Fatigue Initiative including RFA's and Conferences to create interest and facilitate collaboration.

Emphasize how fatigue is a core symptom in many diseases, how little is known about it, the great need to learn more about it, and how ME/CFS -one of the most functionally disabling diseases on the planet -provides a unique opportunity to unlock much that is unknown about fatigue.

At a minimum, fund a four-five day Fatigue Conference to bring researchers from across the spectrum to learn from and interact with and form collaborations with each other.

Give VIcky Whittemore more funding and assistance to carry out her job.

NIH Brain Initiative -many symptoms of ME seem to originate in the brain which makes research collaborations with The Brian Initiative "a no-brainer."

Many patients with ME have symptoms similar to those of TBI, concussion so other brain related research and researchers are likely to be productive areas for collaboration

Cognitive issues are significant for many patients and the inability to engage in cognitive exertion without repercussions (PEM for instance), severely limits the ability of patients to feel meaningfully

engaged in life. Research is urgently needed to find ways of enabling patients to (paraphrasing my sons) 'access their brain at will, without repercussions.' Being able to do so would be a huge improvement in quality of life for many patients -possibly enabling them to resume their education, return to work and/or otherwise feeling meaningfully engaged in life.

Exercise intolerance/physiology as it relates to ME and how it is different than in other illnesses and healthy controls.

Post-exertional malaise -PEM is a hallmark of ME and according to some people in the field also occurs in other illnesses though it manifests differently. It seems that in ME , the triggers, onset, severity, frequency and duration are different than in other diseases/conditions. However, there doesn't seem a thorough scientific characterization of PEM which means that health care professionals and researchers may be missing patients with it or mislabeling patients without it. Therefore PEM needs to be carefully characterized in order to facilitate diagnosis, educate healthcare professionals (and stakeholders) and to elucidate what is same/different about PEM in all conditions in which it occurs. A thorough understanding of the physiology of PEM, the cognitive and physical impact of PEM in ME and of the cognitive and physical triggers of PEM is essential. This characterization should also be done by an NIH sponsored project of ME expert clinicians and researchers as well as researchers in the other conditions said to have PEM. This should be done immediately so as to ensure that the research definition and methods decided upon by ME expert clinicians and researchers will incorporate this characterization of PEM to accurately adjudicate ME patients.

Also, during the NIH conference in April 2019, Dr. Rowe mentioned work being done by colleagues in The Netherlands that demonstrates reduced cerebral blood flow in patients with cognitive limitations (such as those seen in ME) but who do not have positive tilt-table or standing tests for orthostatic intolerance. Because cognitive limitations in PwME are often some of a patient's worst symptoms, and are worse when upright, it could be that current testing for orthostatic intolerance needs to be a multi-step process. (Proper diagnosis of orthostatic intolerance is beneficial because there are numerous treatments that can be tried to help improve quality of life.)

Work strategically to significantly increase the number or researchers and clinicians in the field. Increasing the number of clinicians who can accurately diagnose ME, will increase the number of accurately diagnosed patients which will increase the number of accurately diagnosed people available to take part in studies which will in turn lead to clearer signals in studies.

Pair researchers/clinicians with patients/advocates as mentors to help people new to the field learn how pervasively ME impacts lives.

Workforce training should include presentations by patients/advocate (live, video conferencing, etc) about real life with ME (school, work, SSDI, encounters with HCP, housing, food access, social, etc) to help them better understand the range of difficulties encountered by PwME and as a reminder of why the work they are doing is so important.

For conferences, working group meetings, workforce training etc. include presentations by patients/advocates (live, video conferencing, etc) about real life with ME (school, work, SSDI, encounters with HCP, housing, food access, social, etc) to help them better understand the range of difficulties encountered by PwME and as a reminder of why the work they are doing is so important.

(In 2014 at the IACFS/ME conference, a long-time researcher from a Federal agency was shocked to learn that patients had trouble accessing food and/or had trouble preparing it (for instance could prepare it but then not be able to eat it). She'd been in the field for years but hadn't been "hit with" this detail about the limitations imposed by ME. How many other researchers who purportedly study ME are similarly unaware of the HUGE impact of ME?)

Reminder -oftentimes caregivers observe things patients don't notice and or can more accurately describe what happens to patients, so whenever possible caregiver input should also be used.

Note -see also the MEAction submission:

Workforce Development

with stakeholder participation as an integral component of the education process - Reminder - oftentimes caregivers observe things patients don't notice and or can more accurately describe what happens to patients, so whenever possible caregiver input should also be used.

Interdisciplinary Collaboration

Collaborative Research Centers

SCIENTIFIC AREAS

Microbiome

Metabolomics

Exercise Intolerance

Neuroimaging

Neuroinflammation

Autonomic Nervous System

Neurovirology

Neuroendocrine

Hematology

Immunology

Rheumatology

Nutrition

Emergency Medicine

Integrative Medicine

Fatigue, cancer fatigue

Sleep dysfunction

Orthostatic,vascular dysfunction

DISEASES

Mitochondrial diseases

Connective Tissue Diseases (EDS,etc)

Small-fiber neuropathy

Fibromyalgia

Dysautonomia (OI, POTS, NMH, etc)

Neurologic trauma

Neuroinfections, viral encephalitis

Neurostructural disorders (spinal stenosis, CII, cranial hyertension, Chiari malformation, cervical spine instability, CFS leak, crnail hypoperfusion, etc)

Neurodegenerative disorders (Parkinson's, Alzheimer's, etc)

Neurologic autoimmunities (MS,MG, etc)

Humoral autoimmunities (Hashimoto's thyroiditis, Sjogren's, SLE, etc)

Autoimmflammatory disorders (MCAS< PFAPA/FMF, APS, sarcoidosis, etc)

Immunodeficiencies (hypogammaglobulinemia, etc)

Endocrine disorders (hypothyroidism, pituitary tumor, Hashimoto's,etc)

Brain, pituitary tumors

Migraine

Paralysis, Bell's palsy,seizure disorders, myoclonus, ankylosing spondyitis

Hamatologie malignancies, spenomeggaly (NHL, etc)

Multiple chemical sensitivity, tinnitus Dysbiosis, IBS, SIBO TMJ Adenitis, sinusitis, pharyngitis,blepharitis, optic neuritis Pernicious anemia, hemophagocytic lymphohistocytosis Unexplained infertility (male and female) , endometriosis, vulvodynia
- Create a funding program that is cross disease and cross discipline focused to drive increased collaboration and interest i.e. applications must meet criteria such as including a cross disease aspect in the research question and authors/researchers with multi-disease and cross discipline backgrounds. Provide support and frameworks to help facilitate these challenging complex collaborations. - Related areas include: Multiple Sclerosis, Parkinson's, Pernicious Anemia, Severe Asthma, Tropical Diseases, Sjogren's Disease, Acquired Brain Injury, POTs
In Europe we formed the European ME Research Group (EMERG) project which included other fields of research. This would have progressed further but needed more funding. We can still make this work and join with US researchers.
MEICC criteria
Consultation with the leadership of organizations such as the Open Medicine Foundation, NOVA, the Center for Complex Diseases, Bastyr University, and the Bateman-Horne Center that have already developed processes to increase collaboration and communication.
Once a research area has been targeted, leaders in that area need to be actively recruited. It is important that the NIH be proactive in getting experts involved. In order to make research in ME/CFS more attractive, raise the funding paylines for grants on ME/CFS and make that information publicly known. An active effort must be made to recruit leaders in a targeted scientific area. One strategy that has worked is to include an expert in writing a ME/CFS -centered grant that leverages their expertise. This requires that funding be made available for grants in these strategic scientific areas. The effort to foster collaborations with experts will work best (initially) between peers and at the local level between groups at the same university. It is important for major universities to engage in ME/CFS-focused projects as they tend to set trends for other universities to follow.

Some ideas on this at

http://www.me-ireland.com/research2.htm

Artificial Intelligence and big data

Finding patients.

Other than, start NOW in neuromuscular, cardiac, neurology, â€¦ clinics, I have a lot of ideas on this that could/would contribute to advancement of medicine as a whole, using AI, NLP, and other advanced technologies. It's focused on extracting information automatically from storytelling and getting more complete symptom and time-course descriptions from patients. You have a huge unidentified cohort of ME/CFS 800,000+? If you could ask them to tell their semi-structured stories, and use AI/NLP to extract not just known symptoms, but also look for other trends in symptoms, disease progression, comorbid diseases, clustering of symptoms in subsets of patients, disabilities, names patients use for symptoms…, you could generate an enormous amount of information about the disease, symptoms of the disease and the impact of the disease on patients lives, without the bottleneck of a dearth of doctors. If you put a call out for patient stories, patients confirmed by ME/CFS clinics, the rest of patients who believe they have ME/CFS, and perhaps a different disease whose symptoms don't overlap with ME/CFS very much, I think you would get 1000's of letters, for free, an enormous amount of data. With a promise to de-identify the letters, and an honest broker to send information back to the patients to whom helpful research results may apply, or even a â€œYou may have ME/CFS from our analysis. Please contact a clinicâ€ letter, I think patients (and/or their caretakers in severely affected) would be really excited about participating. You would also have a historical cohort for how medicine can go horribly wrong (i.e. conversion disorder). I can think of a dozen other kinds of projects this data could inform. I also have a LOT of ideas on ways to use AI and big data to make doctors much more effective and make their roles more satisfying and meaningful instead of going in this direction: (NPR health shots news story, "As Artificial Intelligence Moves Into Medicine, The Human Touch Could Be Challenging"). I'm going to send that writing privately because I include my personal story as examples and don't want to make that public.

Late- onset Mitochondrial disease project

I think one really important cohort can be found in late- onset mitochondrial disease. It is very important to send this new information to the mitochondrial disease medical community. Any mitochondrial disease with an onset (after infancy) of a year or less should be re-evaluated for chronic fatigue syndrome. Since it looks like ME/CFS is an acquired type of mitochondrial disease negatively impacting OXPHOS and fatty acid oxidation pathways, any underlying mitochondrial defects could become symptomatic. There is a "threshold effect" theory that people used to try to explain teen and adult-onset in these diseases but there is not much biological evidence for it, and it best applies to defects in mitochondrial DNA, whereas most mitochondrial diseases are caused by nuclear DNA defects. The theory posits good and bad mitochondria duplicate at different rates with more of the dysfunctional ones being created than the functional ones, eventually leading to disease. This theory didn't make sense to me in light of fast onset of symptoms, and I couldn't find evidence for it in the literature. It is possible that nearly all adult-onset mitochondrial disease is actually chronic fatigue syndrome, even with positive genetic tests for mitochondrial disease. It seems entirely sensible to me that a suppression of mitochondrial energy generation from chronic fatigue syndrome would exacerbate or bring to light an underlying mitochondrial disease that was mild in the past. Again the

screen would be for post exertional malaise. Most of the diseases have pretty clear presentations and I don't think it would be that hard to differentiate out ME/CFS. A young athlete with an unidentified fatty acid oxidation disorder like lchad might have a sudden heart attack from an enlarged fatty heart, without ever having PEM, and so wouldn't be a likely ME/CFS candidate. However, an unidentified FOD might result in mild symptoms, like muscle cramping and transient bouts of hypoglycemia requiring whirlpools and candy bars. But if they suddenly came down with the severe version of the FOD, perhaps muscle pain, weakness, spasms, severe bouts of hypoglycemia, muscle breakdown, and also fatigue, it could be that ME/CFS took their fatty acid oxidation down so far that they become symptomatic.

Because they have already been identified to have a mitochondrial defect, this is a good population for exploring natural experiments in how suppression in certain parts of mitochondrial pathways interacts with the chronic fatigue metabolic signature. It could be very helpful to have samples from people with knock-down or knock-out mutations in specific mitochondrial enzymes and also had the chronic fatigue energy production defects, to tease out systems effects in pathways analyses. I think comparisons between human defects in the resulting interactions will help probe for critical pieces of functional, structural, and signaling interactions in mitochondria that result in chronic fatigue syndrome. Perhaps affected mitochondrial disease patients would be willing to contribute blood and tissue samples for this work. I believe there is a tissue bank being built for mitochondrial disease. UMDF.org would know, and Dr. Naviaux.

Toxicology and ME/CFS, preventing harm in patients especially in the emergency room, adding known pathways of mitochondrial harm or modulation to probe ME/CFS molecular models.

Chronic fatigue patients need an emergency protocol letter including medications to avoid, which haven't been identified yet. Lists of dangerous drugs have been developed in mitochondrial disease medicine, and I think they could apply directly to ME/CFS as well, because of the known mitochondrial involvement. Aside from physician input, many drugs to avoid have been flagged in drug companies for mitochondrial injury, and then a kindly toxicologist gives the mito community a list. The drugs have specific actions on different parts of mitochondrial metabolism. For instance NSAIDs directly negatively impact the lchad fatty acid oxidation enzyme and are discouraged for use in fatty acid oxidation disorders. I always wondered why taking ibuprofen made me weaker, but coming across this research revealed the reason. I could tolerate Tylenol if I stuck to times when I had the worst pain. This is not the case in people with some of the other mitochondrial defects where Tylenol can injure them severely. Cymbalta made me much worse, and I had a significant Improvement on stopping it. I think if you had a list of drugs that definitely increase people's symptoms, this could be added to the other metabolic pathway information and models, with help from toxicologists in Industry and Academia. It would also be an extremely useful list for patients . There are common drugs like some statins, metformin, valproic acid, certain antibiotics, that can initiate a permanent case of adult-onset mitochondrial disease in a patient with a genetic weakness in mitochondrial metabolism. These drug injury models could elucidate more mechanisms for driving mitochondria into a dysfunctional state. I think there is a big trove of this kind of data in drug discovery and only some of it has trickled out into mitochondrial disease treatment. So I think the approach right now is to search for metabolic traps and then look for drugs to fix them. But I haven't seen the opposite approach, combining toxic drug impact models to identify metabolic trap mechanisms. Perhaps that is happening and I just don't know about it. But if the reason is that the drug companies are keeping this information private, I think NIH could help facilitate a combined research project there. Or if the reason is that there is not a well-developed approach to be able to

combine that information with expansive metabolic modeling in this way, then that would be a good research project too that could have high impact on many other diseases. It's sort of like probing the systems biology models with different use cases . Since my brain has only recently started working better with the new treatments, I am way behind in following this area, but this component seems to be missing.

-More basic research under the umbrella of "ME/CFS" even if it is not only relevant to this condition. For example, basic research should be asking:

1) what are long-term consequences of nervous system EBV infection

2) what are epigenetic consequences on EBV infection

3) what does the translocator protein (TSPO) do?

4) what microbiome products alter mitochondrial function

5) what functional forms can human glia take, beyond M1 and M2

6) development of better microglia or glia neuroimaging radioligands

7) what are the consequences of peripheral nerve ganglia infection by neurotropic pathogens

8) how does environmental mold effect mast cells

9) how could infection or inflammation increase vulnerability to structural issues like craniocervical instability (CCI); how could they damage collagen for example

10) what systemic factors can activate different tissue-resident macrophage types

These are questions that can be announced under "ME/CFS" but are targeted to basic researchers who don't necessarily normally think about ME/CFS. There are many many other basic research questions that would benefit this condition, I could think of dozens of RO1s.

1. Integrative Physiology, the study of the Body as a Whole. Contact the Physiologist who spoke during the Q&A Day 2 April 5, 2019 of the NIH Conference, 7:17:50 on the livestream, for possible collaboration.

2. Hypovolemia which impacts many bodily systems. Contact NASA scientists who study its cause and effect on astronauts for collaboration with experts.

3. Hypergammaglobulinemia, antibody burden, autoantibodies. Contact NIAID for collaborations.

4. Primary Immune Deficiency Diseases, co-morbid in a subgroup of ME/CFS patients. Contact NIAID for collaborations.

5. Interferon pathway, interferon signatures and interferon paradox. Contact NIAID for collaborations.

6. MCAS/MCS. Contact NIAID for collaborations.

7. Nutrigenomics, nutrition science. Contact the pharmacist and nutritionist who presented at the ME/CFS Montreal Conference, May 2018.

8. Occupational Therapy-- development of treatment guidelines for ME/CFS would be quite helpful.

9. Aging--the study of the effects of aging on elderly ME/CFS patients is needed along with the development of treatment guidelines. Contact NIH NIA.

10. Incorporate ME/CFS cohorts/projects into large NIH Initiatives: "Brain," "Pain," "Precision Medicine," for example.

Having had pain in my legs since childhood (and it may be a personal symptom,) I believe that the pain response to barometric pressure drops, and they must be severe, should be investigated thoroughly for their effect beyond the irritation of nerve sheaths. In addition, electrical aberrations occurring in the electrical covering of the earth, such as typhoons, hurricanes and monsoons can be an issue. I know it sounds strange, but if an ME patient has some small injury, perhaps had outpatient surgery, the barometric pressure and electrical storms can cause horrible crashes in many of us.

One symptom is that our bodies seem to find workarounds for EVERY help we find: i.e., if a supplement appears to help, like vitamin D in good doses, within 6 weeks the effect appears to wear off. And the muscle wasting in animals, (what happened to Cortene? Never worked?) plus their wonderful adaptations such as the hummingbird being able to suspend its metabolism over night, are areas that could impact ME sufferers. It is terrifying to not have ANY strength at all when you go to do something.

Again, start with a basic focus on systems biology, and if possible bring in medical subject area experts from allied systems biology fields into the centers of excellence labs (on sabbaticals?). Grants could help facilitate those types of collaborations.

Scientific Areas:
Neuroimaging
Neuroinflammation
Autonomic Nervous System
Orthostatic, vascular dysfunction
Neurovirology
Neuroendocrine
Hematology
Immunology
Rheumatology
Metabolomics
Microbiome
Exercise intolerance
Fatigue, cancer fatigue
Sleep dysfunction
Emergency Medicine
Integrative Medicine
Nutrition

Diseases:
Mitochondrial disorders
Connective Tissue Diseases (EDS)
Small-fiber neuropathy
Fibromyalgia
Dysautonomia (POTS, NMH)
Neurologic trauma
Neuroinfections, viral encephalitis
Neurostructural disorders (spinal stenosis, CII, cranial hypertension, Chiari malformation, CSF leak, cranial hypoperfusion)
Neurocognitive, neurodegenerative disorders (Parkinson's, Alzheimer's, Huntington's, vascular dementia, frontotemporal degeneration, Lewy body disease, prion disease, normal pressure hydrocephalus, dementia due to HIV infection)
Neurologic autoimmunities (MS, MG)
Humoral autoimmunities (Hashimoto's thyroiditis, Sjogren's, SLE)
Autoinflammatory disorders (MCAS, PFAPA/FMF, APS, sarcoidosis)
Immunodeficiencies (hypogammaglobulinemia)
Endocrine disorders (hypothyroidism, pituitary tumor, Hashimoto's)
Brain, pituitary tumors
Migraine
Paralysis, Bell's palsy, seizure disorders, myoclonus, ankylosing spondylitis
Hematologic malignancies, splenomegaly (NHL)
Multiple chemical sensitivity, tinnitus
Dysbiosis, IBD, SIBO
TMJ
Adenitis, sinusitis, pharyngitis, blepharitis, optic neuritis
Pernicious anemia, hemophagocytic lymphohistiocytosis
Unexplained infertility, endometriosis, vulvodynia

INTERDISCIPLINARY COLLABORATIVE APPROACHES
Barriers:
Investigators with expertise in overlapping domains are ignorant about ME
ME research is currently being conducted in silos
Need mechanisms to link clinicians and researchers
Role of comorbidities, overlapping syndromes understudied
Clinical subtypes undefined
Strategies:
Targeted outreach soliciting proposals from relevant domain experts (senior PIs) (e.g. energy metabolism, neuroinflammation, autonomic dysfunction, mechanisms of central/peripheral asthenia)
Issue FOAs for collaborative projects to facilitate engagement of outside expertise with established ME researchers
Issue FOA for collaborative supplements to existing projects (i.e. NIGMS Supplements for Collaborative Science (SCS))
Issue FOA for interdisciplinary collaborative project proposals (i.e. NIGMS Glue Grants)

Sponsor NIH conferences annually to disseminate findings, facilitate collaborations
Facilitate representation at society conferences, encourage block symposium to elevate disease profile, invite high-profile scientists to leverage star power
Engage in targeted outreach soliciting proposals from relevant intramural and extramural domain experts (senior PIs)
Facilitate matchmaking between domain experts and clinical expertise/bioresources
Compile and disseminate a disease primer/educational video(s) for new investigators of biologic knowns, clinical resources, crash-course on disease-specific issues
Program Officers perform matchmaking between applicants and outside domain experts during grant submission/revision
Issue dedicated disease-specific RFA to entice researchers and clinicians with outside expertise
Create a large data and biorepository for comprehensive study of disease landscape. Leverage the integration database created for the current Centers to store research from present and future ME-related projects. Make data integration a requirement for NIH-funded research on ME. This could include structured and unstructured data with all PII masked to safely protect patient data. Solicit data from other agencies to get a baseline sample set for research. Department of Veteran Affairs has a very large health database, for example.
Exhaustively publicize new disease findings, CRC results
Leverage Director Collins's and Koroshetz's megaphones, utilize every NIH media opportunity available to make the untapped scientific opportunities and plight of patients known within academia and industry
Support development of in vitro/in vivo disease models

COLLABORATIVE RESEARCH CENTERS
Barrier:
Not enough CRCs
Existing CRCs are underspending
Ongoing and renewal funding for existing CRCs not secure
Lack of clinical capacity within CRCs, dependent upon sparse, busy, distant outside clinical expertise
Not enough scientific and clinical outreach, lack of clinical education component
Narrow focus of CRC studies (primarily blood omics)
Not enough collaboration, data sharing
Strategy:
Fund existing CRCs adequately; encourage rapid CRC funding utilization by leveraging follow-up RO1 availability to build upon promising findings; and issue renewal funds at expiry
Issue administrative supplements to support educational outreach to the research and medical communities
Issue administrative supplements to facilitate engagement of outside/overlapping domain expertise in CRC projects
Issue FOA to fund a minimum of three more CRCs with expanded domains of focus
Support new CRCs with a diversity of research domains, for example: characterize functional/exertional features (i.e. Cook, Stevens, Keller, Systrom), neurologic aspects (i.e. Younger, VanElzakker, structural, neurocognitive).
Enforce requirements for collaboration, data sharing between CRCs

Accelerate DMCC construction, analyses, and make CRC/DMCC data publicly available to the scientific community
Heavily publicize CRC existence, publications, study recruitment

WORKFORCE DEVELOPMENT
Barrier:
Ignorance about ME in academic community
Stigma/lack of disease validity in academic, medical community
Lack of senior mentorship support to young investigators, discouragement to enter field
Lack of evident funding stream to entice outside expertise, sustain a dedicated young investigator's career
Lack of accessible bioresources (lack of large biorepository, patient registry, paucity of clinical expertise)
Lack of in vitro/in vivo models to entice outside expertise, sustain a dedicated young investigator's career
High threshold of disease knowledge for entry into the field
Paucity of review materials in literature
Publications often relegated to niche/low impact journals
Psychosomatic narrative continues to pollute literature
Strategies:
Heavily leverage NIH intramural and extramural networks to actively promote disease awareness and scientific intrigue; actively bait interest in disease mystery, novel opportunities for discovery
Leverage Director Collins's and Koroshetz's megaphones, utilize every NIH media opportunity available to make the untapped scientific opportunities and plight of patients known within academia and industry
Engage a concerted campaign to rectify medical and scientific stigma
Sponsor NIH conferences annually to endorse validity, disseminate findings, facilitate collaborations; include dedicated day(s) and poster sessions for young investigators
Require publication of whitepapers out of NIH-sponsored events
Disseminate recorded materials out of NIH-sponsored events
Facilitate representation at society conferences, encourage block symposium to elevate disease profile, invite high-profile scientists to leverage star power
Exhaustively publicize new disease findings, CRC results
Targeted outreach soliciting proposals from relevant intramural and extramural domain experts (senior PIs)
Compile and disseminate a disease primer/educational videos for new investigators of biologic knowns, clinical resources, crash-course on disease-specific issues
Facilitate matchmaking between domain experts and clinical expertise/bioresources
POs perform matchmaking between applicants and outside domain experts during grant submission/revision
Issue dedicated disease-specific RFA to entice outside expertise, demonstrate capacity to sustain a dedicated young investigator's career
Improve perception of limited funds by e.g. broadcasting existing funding availability and SEP support across various institutes, via NIH communiques, Director's office
Issue administrative supplements to support interdisciplinary involvement of senior newcomers

Establish career training and mentorship program for young investigators
Develop and disseminate documentation encouraging young investigators to enter the field, ensure a viable career path
Further support a network of young investigators through the following initiatives: annual NIH young investigators conference; website; Program Officer availability for career growth; grant application support; proactive notification of applicable funding/fellowship opportunities, facilitation of collaboration and mentorship matchmaking dispersal of information on available bioresources; quarterly email updates on new resources/research findings targeted education on applicable funding opportunities; supplement awards to enable young investigator collaborations with established PIs/CRCs; encouragement and sponsorship for society conference attendance; encouraging young investigators to evangelize about ME to their colleagues; and providing materials summarizing research knowns, needs and opportunities
Create a large data and biorepository for comprehensive study of disease landscape
Create a patient registry to support study recruitment and data/sample procurement
Support resolution of clinical expertise bottleneck to facilitate patient/data/sample access
Fund development of in vitro/in vivo disease models
Fund epidemiologic studies
Fund biomarker discovery, disease-specific instrumentation and methods studies
Utilize existing NIH programs and work with other federal and state agencies to incentivize specialization and research via loan forgiveness programs
Pair researchers with patients/advocates as mentors to help people new to the field learn how pervasively ME impacts lives and why work in this field is important
For conferences, working group meetings, e.g., include presentations by patients/advocates (live, video conferencing) about real life with ME (school, work, SSDI, encounters with HCP, housing, food access, social) to help them better understand the range of difficulties encountered by people with ME and as a reminder of why the work they are doing is so important

Headings mentioned elsewhere in this narrative:
Complex Trauma (Gulf War Illness)
Domestic Welfare Policy
Asylum Medicine / Global Health

I would like to make special mention of Dr. Michael J. Lenardo, Chief, Molecular Development of the Immune System Section at NIAID/NIH. My greatest concern for complications attempting to treat trauma ME is the thicket of epigenetic change we expect to find in cases of severe and persistent trauma.

Referencing Dr. Rachel Yehuda's controversial thesis re. intergenerational trauma, I raised the question of epigenetic regulation of immune function in a face to face meeting with Dr. Lenardo after a dynamic presentation he gave at Houston Methodist Research Institute. He explained that the technology has "only just" advanced to the level of sophistication required to identify trauma-induced changes in gene expression. His demeanor felt like a great fit for passionate advocates, and he snapped with enthusiasm at the thought of working with outside groups probing the full complexity of trauma in the years ahead.

N.B. If the NIH Institute on Minority Health & Health Disparities and the National Institute of Nursing Research are not already involved with the ME working group, they should be.
The multisystemic and dysfunctional cascade aspects of the disease should encourage a much needed interdisciplinary approach. It should also attract researchers in emerging disciplines such as symptoms biology (complex interactions and network theory); symptomatology (identifying symptom links and aggregates); epigenetics (investigating gene expression caused by mechanisms rather than DNA); psychoneuroimmunology (focusing on mechanisms underlying brain-to-immune crosstalk); and other emerging fields. Three exciting fields deserve particular mention as both being pertinent to ME and subject areas of Nobel awards over the past three years: autophagy (study of the pathological processes implicit in cell aging); chronobiology (exploration of the molecular mechanisms controlling circadian rhythm); and investigation into the immune-checkpoint blockade (an area with relevance beyond development of cancer therapies).
Runaway inflammation. Causes. Treatments. Immunology. Virology. Genetics. Neurology. Cardiology. Bacteriology.