

Strategies for increasing ME/CFS research collaboration and communication between relevant stakeholders

ME needs a real home at NIH, led by someone who is an EXPERT and will ADVOCATE for it - not this "trans-NIH" working committee. ME is effectively homeless and doesn't have any "house" to live in that will advocate for it. ME--a serious, debilitating neuro-immune disease--was orphaned into the Office of Women's Health that couldn't give it any money. Seriously, NIH - DO BETTER.

You actually have to communicate and take seriously ME patients, advocates, and experts. We've been asking NIH (and CDC) to listen to us for DECADES and you keep not doing it. You can learn from us. Take the time to learn the history of the mismanagement of this disease.

Conferences / webinars / centralised websites.

Strengthen the support groups across counties - eg ME Association, Solve ME/CFS initiative

Better collaboration opportunities internationally

Continue the NIH Accelerating Research Event at the NIH. Continue the Stanford Symposium.

Funding breeds collaboration. They are continually advocating for funding while trying to continue to research. If they receive more funding, this will only help them do their job they set out to do and help each other.

This is where the Open Medicine Foundation model is superior. Having a database of research that any researcher can search and access is key to collaboration. We must get profit out of medicine and focus on helping people over making a buck. Proprietary research has no place in this fight for a cure.

Ditto

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

Work closely with MEAction.

Deal with the individual patient not the organizations who speak for them

Show first that it is real, numbers are what they want to see. How many of us can you handle in different states to interview, survey, test? There are a lot of us suffering and as mentioned before, those that can get to you will find a way to help you show the need, the numbers, the impact, the urgency. If stakeholders are those that want to make money off of new medications, then I'm not sure how to respond. This might not be about a multi-million dollar drug, but the nervous system is broken, if there is funding and profit in the field to try and fix that, you'll get the support you are looking for.

<p>More webinar updates.</p> <p>Can you get Azar to reconsider his horrible decision about CFSAC so we can join together again and meet 2x a year? Or could NIH start something to replace CFSAC? We need something. Our work isn't done and won't be until a cure.</p>
<p>Create a digital hub to connect people and a genetic and bio bank. Or get access to one that's already created. Better yet, make it a part of a precision medicine initiative already started.</p>
<p>These NIH-funded ME/CFS research projects should share their raw data others.</p>
<p>Educate PCPs in this disease. They do not currently have a knowledge base to identify potential sufferers, and are not able to marshal available specialists who are in a better position to treat patients. Many of them are under the misconception that this illness is a mental illness that can be overcome with graded exercise therapy, etc. This is not the case, as many of us who've watched loved ones struggle with this disease are well aware. Educate, educate, educate.</p>
<p>Really, patients need to see some good faith gesture re: funding, after so many years of mistreatment.</p>
<p>create meetings so they can meet each other online or in person</p> <p>online meetings too webinars etc</p>
<p>ATTENTION! MONEY! FUNDING! ATTENTION!</p>
<p>Communicate. Publicity to general public in mainstream media</p>
<p>Patients are exhausted, dying alone, in great pain - TEST something different like acupuncture & herbs that have worked in the east for 2000 years versus 75 year old modern western medicine which has been hijacked by BIG PHARMA profits: over medication is killing already fragile ME patients.</p>
<p>Informacion rigurosa, de la gravedad de la enfermedad.</p>
<p>Webcasting of conferences is really helpful. Recording talks, videos, presentations etc. and making them available online for international collaborators, interested researchers, educational use, to keep patients involved, etc. is really helpful.</p>
<p>- Provide venues that allow input from all stakeholders that is actually taken seriously by the NIH.</p>
<p>Collaboration and communication? Judy Mikovits tried that, see how well it worked?</p>
<p>This is beyond my ability to answer.</p>
<p>Establish a new, permanent CFSAC type Committee which includes all stakeholders. Sponsor the OMF's Symposium, BHC's Clinician Coalition, IAMECFS conferences, etc.</p>

Online database as I've suggested.
A general education strategy about ME for all healthcare professionals
<ul style="list-style-type: none"> - include patients and patients organizations in planning and conducting studies. "Nothing about ME without ME" - promotion of ICC around the world. - exclude all researchers and institutions that use highly inaccurate diagnostic criteria like oxford from collaboration. - better education in med schools. - educate the public. - disease-specific journal - global disease-specific research networks. - more attractive international symposia.
Make a global effort by urging Governments to come together with huge budget. Declare war against MECFS.
Focus on biomedical research
Use establish and strict diagnostic criteria not the untested SEID criteria
Meetings, conference calls, sponsorship at the American College of Sports Medicine's National Meeting of Symposia etc.
Include us - make videos, audio tapes and transcriptions of all shared research efforts.
Money.
Talk with Www.emerg.org.au & the Open Medicine Foundation who are doing this well already.
<p>As mentioned earlier, tech geniuses could write a program for sorting and matching all research and clinical trials - whether completed or in progress - a program to be made available internationally. As doctors from many countries have researched this illness, it could be a way to share information in real time.</p> <p>The program could include a suggestion box. Even though this might invite some crazy suggestions - an observant patient might hit on something that proves to be the key.</p>

Funds.
US medicine is grossly inefficient so need more collaborations, other perspectives from rest of world incl Carmen S in Berlin, others in Norway, Sweden, Belgium, Spain, Italy, Japan, New Zealand, Australia and perhaps others. The insight and cures might come from any continent
-digital engagement platforms -simplified versions of papers published (designed to reach a general audience)
Do more social edit Campaigns to educate people and acquire participants for studies or to tell their personal stories living with cfids
Centralize information in a MAJOR dedicated website run by a webdeveloper and 2-3 content experts who can review subitted information. In effect, a clearing house of cuurent information and Opportunities that can then be publishized through all ME/CFS NGOs
Establish an easily accessible, national database and online forum in which all stakeholders can post ideas, questions, potential research studies, preliminary findings from studies large and small, and conclusions from research that has been completed. Get the word out to all concerend about this opportunity to collaborate.
See above
I would recommend approaching the Lyme Communities, not the Lyme-denying Infectious Disease doctors such as Gary Wormser who had conflict of interest and wrote the 2004 guidelines. Try Brian Fallon and try to doctors who wrote the ILADS guidelines.
Creating plans and following through on commitments to keep stakeholders updated with all findings which will establish trust and allow the funds to flow to further clinical trial studies with the goal of finding a cure.
If there is a disconnect between research and stakeholders then open the lines of communication, offer meeting tours, newsletters, whatever crosses that bridge. Educate them somehow. Tell them the results, and show them the connections you are making, show them that this has a future as far as possible drug development as well. I assume you mean stakeholders as in stock? Ask, ask, ask, you need to tell them what you need, plan and simple we need this, can you help us. They can't read your minds, so tell them what you need.
Communication and transparency without the consideration of profit and corporate or political agendas.
Release a common research tool and social network for researchers to collaborate on projects in teams and share data with incentives being credit and recognition. Looking into trans-adapting diagnostics and treatments for AIDS to other various Herpesviridae that have been implicated in Fatigue.

A national biobank for ME/CFS. Encouraging collaboration.
Establishing centers of competence and research that have doctors and scientists who are of different specialties working together as clinicians. The patient should not be the one to find all the specialists who might help. They should be in one place or at least connected virtually and consult one another.
My hope is that the NIH (maybe with the CDC) can become the communication link between relevant stakeholders.
It is important that someone be in charge.
Massive increase of funding.
Increased funding.
As mentioned before, interact with patients via patient forums. Typically you will find membership of forums to be those with more lived experience of ME/CFS, and with the communication skills to express them. Again, I would flag up Science for ME, www.s4me.info , as a forum that welcomes researchers joining and interacting with patients.
Meetings, conferences, ongoing education to stress need for funding this research as well as stressing the importance. Patients sharing more of their stories when possible, as well as their caregivers.
Get more authors on the subject to write about ME in medical journals, magazines and for publications aimed at the general public. This will draw more willing stakeholders.
More CRCs
-
<p>Science for ME</p> <p>The online forum 'Science for ME' (www.s4me.info) has proven to be a fruitful collaboration between ME/CFS patients, carers and scientists. Established in 2017, Science for ME is an open, international forum where ME/CFS news and research is discussed with respect to the views of all participants. Members of Science for ME have been vital in the reanalysis of the PACE-trial and have submitted detailed responses to the Common Data Elements for ME/CFS regarding the measurement of post-exertional malaise and the Chalder Fatigue Scale. Members include respected researchers and patient advocates such as Jonathan Edwards, Carolyn Wilshire, David Tuller, Tom Kindlon, Simon McGrath and Suzy Chapman. In the patient community the forum is known for its skepticism, open debate and scientific rigor.</p> <p>I think Science for ME would be the ideal forum for collaboration and communication between the ME/CFS research community and other stakeholders.</p>
Set up a task force with a balance of interests and follow Robert's Rules of Order to achieve consensus.

<p>This is a huge challenge with researchers that have huge egos and want to be THE one to solve some aspect of the disease. NIH needs to assert itself more aggressively to make researchers accountable for collaborating and not letting researchers not show up for mtgs without consequences</p>
<p>Provide venues that allow input from all stakeholders that is actually take seriously by the NIH.</p>
<p>Fund the various collaborative meetings.</p> <p>EMERGE Australia.</p> <p>Invest in ME Annual Conference.</p> <p>etc, etc</p>
<p>FUNDING</p>
<p>Facebook page; central location for doctors and scientists.</p>
<p>Have the NIH funded research centers collaborate with the Open Medicine Foundation and its 3 research centers, Nancy Klimas and her work and other investigators doing large amounts of work on ME/CFS.</p> <p>Expand the field of stakeholders to include all serious fatiguing disorders. Fund a review in a journal which examines the fatigue findings in all fields.</p> <p>Find a way to support the IACFS/ME's fatigue journal through editorials, studies, ?...with the recognition that it is the only Fatigue journal present</p>
<p>Having a centralized authority for information, rather than a loose federation of non-profit groups.</p>
<p>Make it compulsory that research is shared. Share, share, share, Have the NIH funded research centers collaborate with the Open Medicine Foundation and its 3 research centers, Nancy Klimas and her work at Nova Southeastern, Jarred Younger and the University of Alabama, Birmingham, and other investigators doing large amounts of work on ME/CFS.</p> <p>Expand the field of stakeholders to include all serious fatiguing disorders. Fund a review in a journal which examines the fatigue findings in all fields.</p> <p>Find a way to support the IACFS/ME's fatigue journal through editorials, studies, ?...with the recognition that it is the only Fatigue journal present</p>
<p>Open access to data is a good start.</p>
<p>Utilize ultra experienced, super effective, extremely positive, goal-oriented and charismatic communicators and scientists</p>
<p>Funding commensurate with the enormous need.</p>

Again, visibility and understanding of how debilitating this condition is is paramount. Making people aware of it and breaking the myth that it's all "in your head" or "not really a disease".
Educate doctors and public
An institute with help with funding would be the best I think.
Ads that show these people with their stories to any healthcare professional or the community as a whole. Just getting the word out there will bring them together.
Make it all about working together in the exciting field of ME. Make everything centred around the patients voice and experience and let the community do the rest, after all they have been doing it for decades.
Have the NIH funded research centers collaborate with the Open Medicine Foundation and its 3 research centers, Nancy Klimas and her work at Nova Southeastern, Jarred Younger and the University of Alabama, Birmingham, and other investigators doing large amounts of work on ME/CFS.
I suggest you listen to the OMF foundation and the SMSCI organizations and listen to respected ME/CFS researchers, like Nancy Klimas, etc.
Host more general topic meetings, such as fatigue research near-immune illnesses, or syndromes.
How was this overcome for Parkinsons, HIV, MS....
Whatever collaboration and communication that could be improved should be improved as technology allows, conferences seem to be helpful also
Centralize a database of trials/studies that announces upcoming research proposals/methods and the results of ALL studies about ME/CFS. This bypasses publication bias and makes it easier for non-researchers, such as medical practitioners and caregivers, to keep up with current studies. It also makes it easier for researchers to coordinate their efforts.
Hmmm, you're asking me to tell you how to eliminate selfishness, ignorance, greed, professional rivalry and ego? Will need more time for that one!
no idea, but my brain has officially shut down
I believe there are already measures underway.
Same as above.
I don't know if there is a specific ME research journal (either in print or online), but if there isn't , one should be developed. All relevant parties should be able to access it easily and with little or no cost.
A registry of all researchers doing work relevant to ME including their area of expertise, current research, hypothesis, institution and contact information could be helpful.
??? Ron Davis and others are way ahead of you. You missed the boat on meeting our needs. Make it up to us by actions that show you take responsibility years of cover up and damage. You have a lot of power ...use it for good!

Trust me, if you had this disease, you would be doing whatever you can to rid yourself from it. I know, I almost died two years ago. It is hell. Fortunately I have a husband who supports me.

More immediate sharing of knowledge. Having a small cohort study followed by other small cohort studies takes forever. I've already been missing from 30 of my 60 years. Hurry up!

An app for patients to record symptoms

Reach out to patients. Let them know the progress and direction of research and funding. Give them an opportunity to join any studies or to put their names down to participate if they are needed.

Coalition groups similar to Dr Bateman's; more frequent consortium groups, inviting local health professionals in different locations of the country (and/or online participation). This could be spread country-wide. I am a (or, I WAS) a physical therapist and want to put together some kind of education program for PTs because I have had colleagues that know I have ME/CFS call and ask what to do with patients ME/CFS.

Regular NIH-backed conferences / symposia

Open sharing of research data on centrally-controlled (e.g. NIH) databases - so studies are not unduly replicated, especially if negative studies

More regular conferences to exchange information. The recent meeting in Bethesda was so heartening for those of us who have had this disease for 30+ years.

Common databases and information sharing. Knock down those silos.

Peer to peer conferences

Establish a national U.S. database of ME/CFS patients that relies on voluntary self-registration and allows patients to submit and update their information and details directly, instead of relying on a doctor or healthcare professional to do this for them. Researchers could view the reliability of this data accordingly, but if/when ME/CFS patients do have a primary care provider who is participating in their care, and/or if they have in past received a diagnosis from an ME/CFS researcher, that information could be logged and cross-referenced or verified with the relevant offices.

- international working conference for said stakeholders; I suspect it will take years to develop good understandings and relationships

- advertising to relevant stakeholders in countries where ME/CFS is still an unknown entity

Funding.

Create a database fed into by patients through forms like this, searchable by key word by researchers and practitioners.

The site would also provide intuitively communicated information uploaded by researchers, and maybe practitioners about research, trials, and maybe protocols.

The site would use an intuitive user interface. This would not only aid communication between those traditionally thought of as stakeholders but with a section for testimonials in video or writing could also raise awareness.

The site should also have an open source section of patient biometric information, with the dates and time of testing, from cytokines, to dna, to epigenetics, uploadable by patients themselves practitioners, or researcher, the latter having their data marked with the special status of trial/control status, all of which should be easily downloadable and formatted for easy input into machine/deep learning programs.

A graphic section to represent the biometric information and economic impact information in graphs should have its link disseminated to individual professors with relevant classes, like public health or development, so as to be an example of the link between health issues and economic issues, and in so doing raising awareness.

Campaigns to call news organizations from 60 minutes to Vice news to local news stations by stakeholders to tell them about a relevant story should be organized. It should include standardized emails which can offer to connect such news organizations with willing Researchers and stakeholders, like Ron Davis and his family, Maureen Hansen and hers, or people at the 'Open Medicine foundation' or 'solve me/cfs' organizations.

Contact state groups organized as ME/CFS advocacy groups and invite participation.

HUH?

CLEVELAND!!!

Use their health coaches to help overcome barriers to participation. Use [...], he had CFS! Look at him now!

Phone calls, webinars, webpages, email lists, utilize the groups for ME/CFS patients to get info out. More questionnaires like this, where the people with ME/CFS and their care givers can have input and make suggestions.

Patients and ME providers work well together in pursuing research studies as evidenced by the NIH Conference. Accelerated funding is needed to address the serious underfunding this illness has received to date. The major strategy needs to be equitably resourcing this illness, just as it was at the beginning of the HIV pandemic. ME patients are less visible than HIV patients due to the severity of their illness. Education of medical and mental health professionals will improve this situation. Equally, the public needs understandable information to counter the persistent stigma.

ME researchers and doctors should form their own professional organization independent of CFS, ME/CFS, and chronic fatigue organizations.

- Share the information! Have the NIH-funded research centers collaborate with the Open Medicine Foundation and its 3 research centers, with Nancy Klimas and her work at Nova Southeastern, with Jarred Younger and the University of Alabama, Birmingham, and other investigators doing large amounts of work on ME/CFS.

<p>- Expand the field of stakeholders to include all serious fatiguing disorders. Fund a review in a journal which examines the fatigue findings in all fields.</p>
<p>There are no such stakeholders as a disease named 'ME/CFS' does not exist.</p> <p>ME stakeholders communicate fine already and will start collaborating as soon as there is funding.</p>
<p>Money for conferences, workshops; use online communication/video conferences; money for up-to-date communication technologies; use open access data archiving and sharing, use strategies from rare diseases research (e.g. prefer - but do not restrict - grant applications with at least 2 or 3 research institutions); enable international collaboration.</p>
<p>All relevant stakeholders need to put forth major efforts to dispel all stigmas related to the illness and create a medical environment where when a patient goes to a doctor, the doctor can no longer say that he/she has "never heard of myalgic encephalomyelitis." All stakeholders need to invest adequate amounts of financial resources into CFS/ME research, and by adequate I do not mean "increase marginally" I mean equal the financial resources of similar yet less severe and less common illnesses that receive quadruple the funding which are not even starting from ground zero like ME/CFS is. In terms of general advocacy, too much emphasis and responsibility is placed on the actual patients to protest, advocate, and educate, meanwhile we can't even sit up half the time. I think many organizations advocating and trying to spread awareness mean well but are not comprehending that the subset of people they are advocating for are actually too sick to participate themselves. That is why every demonstration is too small or too unorganized to garner any real attention. I believe the scientific community, the NIH, and caretakers/friends/family should be most pressured to advocate and spread awareness.</p>
<p>Open data approach as per OMF.</p> <p>Conferences such as recent NIH Conference and possibly more technical meetings (lead by NIH) aimed at transferring knowledge between teams.</p> <p>Communications; involving key individuals from the patient community - such as Jan Brea.</p>
<p>Patient identification and diagnosis</p> <p>Physician and health care provider education</p> <p>Epidemiologists</p>
<p>Utilize research collaborations such as the two in Houston between Rice University, Baylor University, Methodist Hospital, University of Texas Medical etc etc etc</p>
<p>There are many demographic groups that are being ignored in ME/CFS research. Supplemental funding to build the community partnerships and strategies needed to expand study recruitment into these historically underrepresented populations is critical to understanding this complex disorder.</p>
<p>Must make everyone aware of the magnitude of those suffering from the illness and that they generally can't take most actions on their own. The medical community must also be educated more regarding the illness. And funding must be significantly increased.</p>

STAKEHOLDER ENGAGEMENT

INTERDISCIPLINARY COLLABORATIVE APPROACHES

COLLABORATIVE RESEARCH CENTERS

WORKFORCE DEVELOPMENT

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!!!

It might be helpful (especially once a diagnostic test is discovered) to set up a registry of patients who are willing to participate in studies, clinical trials, etc.

Increase number of international research meetings. Financing doctors', researchers' and students' participation in such meetings.

- Ask the Secretary of HHS to reinstate the CFS Advisory Committee (CFSAC). CFSAC provided an excellent forum for communication and collaboration among researchers, clinicians, patients and patient advocates.

- Sponsor an annual conference on ME/CFS Research. The April 2019 conference on Accelerating Research on ME/CFS, including the workshop for young investigators, was inspirational and should be repeated annually.

Respond with strategy demonstrating that NIH feels urgency about the situation and intends to move mountains to make things change quickly, ramping up funding quickly and increasing availability of services quickly. We have seen you move mountains and get things done quickly for other conditions. If you're not doing this for us, we don't believe you're taking us seriously. Just because it's chronic doesn't mean it's not an emergency. A serious disease with a huge number of undiagnosed patients and more with essentially no clinical care is a public health emergency. NIH and the other federal agencies should treat it like one.

We need to devote the resources to those who have been assigned the task of developing and running task forces and other committees. The way I see it as things stand now, individuals are given the work on top of their already full plates, which creates resentment and lack of motivation.

Collaboration between stakeholders who are not working on the same patient groups is unproductive. Those who fit the ICC should NOT be lumped in with patients who do not fit that criteria. All patients need to be evaluated using the ICC.

Patient engagement sounds like a great idea. Someone should try it someday, a process which would involve recognizing patients as primary stakeholders in the process and outcome. The current status

quo was created with systemic hostility to patient experience, a process that lead to predictably horrible outcomes.

Grants, scholarships, fellowships

)

annual NIH MECFS conference.

ADVERTISE widely to NIH depts./ university researchers/ etc.

When multiple proposals must be written to obtain any funding, and the funding received is barely sufficient to carry out the project, it is difficult for researchers to allocate as much time as they might like to engage with stakeholders.

1. The general public may have no, little, or wrong ideas about how research is planned, implemented, analyzed, interpreted or disseminated. They may not comprehend the challenges of research. They may also not know how to find out about current ongoing clinical trials, which factors to consider when enrolling in a trial (e.g. for example, that the responsibilities/ expectations of researchers towards study participants is different from that of treating clinician and patient), what NIH's specific mission is nor how it is operated (e.g. the types of research NIH usually funds and does not fund, how grants are selected). Although these issues are not specific to the ME/CFS community, any resources created/ provided by NIH regarding these topics might be helpful.

2. Consider including the input of outside stakeholders when constructing RFAs or Program Announcements of ME/CFS and when reviewing grant applications. Currently, for example, the Department of Defense's Congressionally Directed Medical Research Program includes patient or caregiver reviewers in their grant study sections and requires all grant applications include at least a lay abstract which summarizes the research in plain language. This reminds researchers to think about the potential practical applications or real life implications of their work. We have heard from lay reviewers that they value their inclusion in this process. Similarly, consider including community-based (i.e. not only university-based) healthcare professionals who take care of the majority of patients in the US. We recognize this is not an easy process since the public must be given some baseline education about the purpose of and how research works. Furthermore, the implications of research may not be predictable early on. However, ultimately, the public pays for NIH-funded medical research and are the direct consumers of it while community-based healthcare professionals are the ones who carry out care.

All NIH studies using the ICC to select cohorts should be clearly identified as such and there should be a mechanism whereby these investigators can communicate with each other - thereby facilitating like-studies collaboration. .

The organization, MEadvocacy.org, who represent people with ME as defined by ME experts (ICC) should have representation on all NIH working groups and on any other discussion and decision making panels with accommodations for the advocates' level of illness. Additionally, they should be listed as an ME organization on all advocacy/patient groups such as Medline, NIH ME/CFS website, CDC website, etc.

Interestingly collaboration between researchers is not a big issue in ME/CFS, being a small research community the big players in ME/CFS research already know each other well and speak with each other relatively often at various conferences and for coordinating their approaches. Many have affiliated with OMF and those who have not often collaborate with each other on findings and new directions to go in.

If the field does increase with NIH support this could become a challenge but at this point this is not an issue and unless things change it will never become one. It would be a good problem to have if more people came and stayed because they had a future in ME/CFS research.

Also MEAction and several patient forums such as S4ME and Phoenix Rising are very active in keeping up with the current science and would assist with research collaboration and communication where appropriate.

(need to rest now)

Share, share, share, Have the NIH funded research centers collaborate with the Open Medicine Foundation and its 3 research centers, Nancy Klimas and her work at Nova Southeastern, Jarred Younger and the University of Alabama, Birmingham, and other investigators doing large amounts of work on ME/CFS.

Use Department of Defense funding to increase funding as Nancy Klimas suggests.

Work strategically to significantly increase the number of 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?)

Ensure that (stakeholders patients, advocates, caregivers, etc) are part of all projects (from inception to completion to publication of results to follow-up) related to ME.

Transparency in all agency (within HHS also) areas re things related to ME (for instance - for the Trans-NIH ME WG, we have no idea how many members meet, how often, what transpires, what gains they have made, etc.)

We are often told that the Trans-NIH Working Group is taking input from the community but we do not have a clear understanding of how often the working group meets, who takes part in the meetings (as opposed to who is on the roster), what is discussed and how in fact the group spreads the word, makes inroads for ME in their respective institutes. Have stakeholders presented to the group? Are stakeholders involved in the group on an ongoing basis? If not, WHY not and how soon will that be changed?

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.

Stakeholder Engagement

- must also include caregivers -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

- Inclusion of patient carers/advocates as a proxy for patients

- Increased PR on the disease and the latest discoveries to increase awareness

MEICC criteria

- Not waiting for researchers to come to the NIH, which is "business as usual." This has not been effective and is holding progress back. The NIH should take the initiative to set out research goals for ME/CFS, including both basic research, but also testing of various treatment modalities being effectively used by ME/CFS experts, dysautonomia specialists, functional medicine doctors, and naturopathic doctors today, with an eye to finding what is effective, for which groups of patients, and getting the word out so that more patients can improve faster.

- Taking leadership in promoting greater understanding of ME/CFS, the current state of research and treatments being used for ME/CFS among researchers as well as healthcare organizations and their databases. Much info available on major healthcare institution and university websites is scanty and out-of-date, still promoting treatments like antidepressants, CBT, and GET, which are no more

effective for treating patients with ME/CFS than those with a broken leg or cancer...

- Funding Centers of Excellence where stakeholders can interact and participate in research.

- Requiring communication on the NIH website and by Centers of Excellence.

Strategies suggested here at <http://www.me-ireland.com/research2.htm>

The text I put in the previous section "strategies for overcoming scientific challenges..." belongs here too.

Part of the text I put in the previous topic "Identifying related scientific areas..." belongs here too. so I am duplicating it here.

Artificial Intelligence and big data

Finding patients.

Other than, start NOW in neuromuscular, cardiac, neurology, ... 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 "You may have ME/CFS from our analysis. Please contact a clinic" 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.

-Support from NIH in regards to Material Transfer Agreements (MTA) and sample sharing across sites. For example, providing templates and placing them in a centralized page on the NIH's website. Better still, make the NIH the central hub for sample sharing. As is, we are seeking approval - separately - to share or receive samples with UCLA, Dartmouth, Broad Institute, private hospitals, etc. It would be helpful if we could fill out an MTA for some "NIH Sample Sharing Consortium" that allows us to share with many different institutions at once, instead of receiving permissions to share with each institution separately.

Develop a comprehensive plan to manage and disseminate ME/CFS Research/Clinical Information as follows:

1. Hold "Accelerating ME/CFS Research Conferences" annually or more often when warranted.
2. Design a post-conference website that pulls together in one place all Conference materials: the Program, Speaker bios, brief summaries of talks with key slides; separate videos for each talk, image gallery, etc. See Emerge Australia's website: <https://mecfconference.org.au> as an example.
3. Work with the livestream vendor to prevent future livestream transmission problems which prevented many patients from viewing "live." Note as of today the 2-day livestreams combined have over 12,000 views.
4. On an on-going basis "synthesize" and publish key ME/CFS research presented at all conferences, i.e., Montreal, 2018; London 2018; Australia, 2019: OMF, 2018.
5. With his permission, format Tony Komaroff's summary presentation as an "ME/CFS Introductory/Overview" presentation for others to use.
6. Use every opportunity to speak publicly and publish information about the exciting ME/CFS research underway highlighting opportunities for new and early career investigators to enter the field.

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Researcher collaboration is easier today than ever, using online meeting systems. Scheduling regular meetings helps. I work with a scientific society where we have a one hour meeting at the end of each week, using an online meeting software system. We meet with collaborators all over the world this way. We have two meetings on the meeting day, 12 hours apart, to include everyone internationally. That approach, combined with an open conversation type of management of the meetings, seems to work very well. Researchers do not need to be led around, they need to interact in a open, ego-free environment. This can be done today very affordably. (we use the Bluejeans.com system, it works very well)

STAKEHOLDER ENGAGEMENT

Barriers:

Dissolution of CFSAC has left the ME community with no channel through which to communicate needs to NIH or other federal agencies

No specific venue within NIH for community engagement

Lack of transparency and community engagement with the Trans-NIH Working Group

Sparse disease-specific information and resources available online

Lack of venues for researcher engagement with patient/caregivers to understand disease features

Level of patient physical and cognitive impairment, disability and lack of financial resources

Not enough CRCs

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

Not enough collaboration, data sharing

Strategies:

Leverage Director Collins's political capital to ask HHS to restore CFSAC

Develop a structured, NIH-led venue focused on advancing research that engages: ME patient, caregiver, and advocate communities; clinical communities; research communities; relevant NIH institutes; other federal agencies; academic institutions; medical and scientific societies; and the pharmaceutical industry in order to:

>> undertake a holistic approach to the wide-ranging problems impacting ME research

>> engage cross-agency collaboration in resolving interrelated and interdependent bottlenecks in growing the field

>> provide leadership and structure for a venue which facilitates movement on key issues that fall outside NIH's remit (e.g. HHS, Department of Education, SSA, VA) but impact the community and ultimately the capacity for growth in NIH-led research (such as diagnosis, clinical care, medical education, school accommodations, social security disability, and medicare).

Establish Trans-NIH Working Group transparency and stakeholder engagement

Proactively leverage Director Collins's and NIH Institutes' political capital and networks to increase disease awareness and active engagement among medical and scientific societies, academic institutions, and federal agencies

Leverage NIH intramural and extramural networks to promote disease awareness and scientific intrigue; actively bait interest in disease mystery, novel opportunities for discovery

Initiate a concerted academic awareness campaign to bait scientific interest

Leverage Director Collins's and Koroshetz's digital megaphones, utilize every NIH media opportunity available to make the untapped scientific opportunities and plight of patients known within academia and industry

Initiate a concerted public awareness campaign to rectify medical and scientific stigma

Fund additional CRCs

Encourage/require and support CRC education, clinical training, outreach efforts

Sponsor NIH conferences annually to endorse validity, disseminate findings, and facilitate collaborations; include dedicated day(s) and poster sessions for young investigators, and invite the patient and advocacy communities to attend and participate

Disseminate recorded materials out of NIH-sponsored events

Require publication of whitepapers 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

Compile and disseminate a disease primer/educational video(s) for new investigators of biologic knowns, clinical resources, crash-course on disease-specific issues

Facilitate matchmaking between domain experts and clinical expertise/bioresources

Initiate and host digital roundtable events between researchers and patients/caregivers to facilitate discussion and brainstorming around key issues in ME research (e.g. barriers to study participation, what PEM feels like, triggers of PEM or long-term relapse)

Include ME in the list of diseases on the NINDS website

Expand the NIH digital space addressing ME research to include recorded materials (conference presentations, links to CDC resources), disease-specific educational materials for researchers and newcomers to the field, links to patient registries and available data/biorepositories, links patient support/advocacy organizations

Disseminate new research findings, funding opportunities, study recruitment opportunities, event notifications via listserv
Support a patient registry to facilitate study recruitment and data/sample procurement
Establish and maintain NIH-funded centralized data and biospecimen repositories, which can store anonymized clinical and research data including imaging data, and biospecimens collected from well-characterized patients in past, current, and future research studies, including existing repositories.
Make accessible to outside researchers.
Fund epidemiologic studies
Support resolution of clinical expertise bottleneck to facilitate patient/data/sample access
Fund, convene and maintain a clinical network leveraging clinical and scientific expertise
Document, operationalize and encourage dissemination of clinical expert knowledge to researchers and the medical and patient communities

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

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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

To me, the most important energy for ME/CFS research collaboration and stakeholder involvement is pressure to innovate because (1) the current drug development process is clearly not sustainable, in general, and (2) ME clinical trials remain the elusive holy grail.

I am interested in exploring community-based participatory action research and alternative trial designs under headings like “patient-centric,” “precision medicine,” and “real world data trials,” but this is an arena in which I am more likely to be an earnest learner instead of conceptual leader.

I know that reducing data silos is essential, to enable sharing and transparency in communications. Integrating patient registries must be a sub-goal, but I need further training I have not yet found to contribute effectively or feel confident making suggestions. [...]

Enabling the patients to better inform the experts is crucial to moving this field forward.
Doctors know medicine. Researchers know testing methods. Only patients really know their own illness experience.

Avenues must be created to enable patients to become collaborators, particularly with respect to delineation of illness presentation, therapeutic preferences, disease management, and outcome measures. Scientists may have considerable scientific expertise, but they often bring biases to the table and lack in-depth knowledge of their subjects.

Human beings are not mice. They do not live in a lab. They have personal histories, life experience, priorities and needs often overlooked by investigators. Those differences need to be recognized and better explored. Not only would researchers gain invaluable information about their subjects, but research design and priority settings could be improved to create larger cohorts and more sophisticated benchmark schemes. For example, patients who are unwilling or unable to travel to major medical center settings could help researchers design methods which collect data via internet applications or which pool data from multiple primary care tests. This could reduce the confounding factor of patient exhaustion involved in evaluations which require travel and large time commitment.

The number of patient advocacy groups involved in informing the process should be expanded. Funding should be set aside to help these organizations help HHS by identifying means of informing the field in an organized, methodical manner.

Oversight by NIH . Hiring of a "project manager" to keep up with all research in the field and obtain feedback from investigators. NIH then sharing with the public all information gathered.

Take any mecfs please