

Approaches to strengthen research and career training for ME/CFS investigators

ME/CFS investigators should spend time contacting patients to find out more about their illness. Patients may have a trove of information about their illness to share and lead researchers in the-right direction.

If they're not taught about it in school, and if NIH keeps funding irresponsibly low, no one is going to want to specialize in it.

Get correct information to med schools. Get it taught in the med schools. Get it on the boards exams.

Offer an appropriate amount of funding for biomedical research through RFAs. If you offer REAL money, the researchers will come.

CDC in 2017 FINALLY removed recommendations for Graded Exercise Therapy and Cognitive Behavioral Therapy from it's ME web page. However, it needs to proactively send out information that it has removed those recommendations, and that those previous recommendations were wrong, unhelpful, and possibly harmful, so that everyone gets the memo.

Support through national /international networks.

Better education materials for professionals.

Teaching ME/CFS in Medical Schools

Open up funding, increase public awareness. I believe public service announcements about the effects of Myalgic Encephalomyelitis on individuals, families, and communities would do the trick. I volunteer to have my story told. Please contact me.

Targeted new investigator, RO1, RO2 and R21 grant RFAs.

Targeted outreach to PhD students; predoctoral support to students via their medical school administration.

More money.

Modern medicine has physical, chemical and biological diseases. CFS / ME should be classified as a new disease. In the case of automobiles, there are many maintenance centers, which periodically exchange oil, wind the wheels or replenish the cooling gas. In this way, I think that it is necessary to have an area that makes the optimal condition periodically for the human body to behave normally.

Do not diagnose patients with ME or CFS because you can't find anything else wrong.

Require medical schools to teach a curriculum

And require graduated docs to attend classes

Funding, Sifting out the too many symptoms, get to the stronger commonalities.
Hold more ME scientific meetings, offer scholarships, set up preceptorships for young medical providers, scientists, and investigators to shadow experts (Levine, Kauffman, Montoya, Bateman, etc
Have them talk to patients about formulating questions correctly. A lot of questions made for research sometimes do not represent patient experience.
To fund them is the most important thing. The NIH should spend the research dollars to more junior investigators. A recent report says "Small research teams 'disrupt' science more radically than large ones" (https://www.nature.com/articles/d41586-019-00350-3).
Unknown
-include it inside other university programs ie cancer, parkinsons, MS etc -make it fashionable, trendy -money
ATTENTION! MONEY! FUNDING! ATTENTION!
SEE ABOVE
More money from the government
Chinese Herbs & Acupuncture is the only tool currently working for those few patients who have resources & some remaining strength to access it...
As above - conference attendance grants and doctoral scholarships. You could also find postdoctoral placements, and CPD training for established researchers. CPD accredited online training for researchers and clinicians would t really helpful.
-Spend more time and energy promoting information about ME/CFS. Have key people in positions of influence inform the people they work with (from PhD students they work with to colleagues etc) through blogs, official statements etc. (it's difficult to become interested in researching a disease you

<p>know little or nothing about - i.e., its severity of debilitation and prevalence). An example of what I'm saying here is Walter Koroshetz's and Francis Collins's 2017 blog "moving toward answers in ME/CFS." We need a LOT more communications like that blog coming from people of influence</p>
<p>Just tell them to memorize the three words patients of this cursed illness know and hate - 'needs more study'</p>
<p>Have a central clearinghouse for suggested areas of follow up on the gaps and questions raised in the current NIH clinical research. Make it easier to partner with them. Provide established researchers the funds to mentor new investigators. Deem this a worthy cause and develop criteria for paid internships as in other technical fields.</p>
<p>This is beyond my ability to answer.</p>
<p>Utilize the ECHO system like Bateman Horne Center. Offer scholarships to new investigators for membership in IAMECFS, or to attend relevant conferences.</p>
<p>They need more money and institutional support and clinics and labs and cross collaboration. Talk to OMF who now has 3 working groups. Share your information and collaborate. Become a consortium.</p>
<p>This needs to be part of a much wider education strategy</p>
<p>same as above</p>
<p>Special centre dedicated to MECFS Research.</p>
<p>Because the disease has so many manifestations, researchers must be drawn from multiple disciplines.</p>
<p>Use of the International consensus criteria for ME to be promoted with all trained on it</p>
<p>Avoiding any rehabilitation only research given that this illness does kill and there's no way to tell who will recover</p>
<p>Training Awards, eg. K01 for PhDs</p>

EDUCATION AND INCLUSION OF PEOPLE WITH M.E. IN VETTING OF ALL TRAINING MATERIALS.
Money.
Guaranteed long term funding.
Educate all physicians, neurologists, rheumatologists nationally to know the ME/CFS diagnosis.
Fund trips for younger researchers
Provide orientation and access to the doc film on cfs by a Harvard grad student.
Enhance visibility of cutting edge work in mainstream medical publications such as Annal of Internal Medicine to provide extrinsic reward to young researchers needing recognition.
Have potential investigators shadow a patient for a day or a week. Or at least interview some number of patients and caregivers. Fund meta-data studies of all existing ME/CFS research. Publish the findings.
More funding, collaboration and offering internships.
Maybe for med student to do research offer them credits for their courses. There is a lot they can do to earn credits for their college classes. It would offset some of the low level work that you would otherwise have to pay for. And it can work at any level, many student just want to get into that lab. Offer them a set amount of time for their own research in exchange for your research. Maybe even offer residences in certain fields.
Look beyond the numbers and data sets and talk to the patients that live with this illness. Many of us have had to become our own medical experts (myself included) and we may not be doctors but we know what does and does not work for us. We can also provide significant details about how we got sick.
Offer parallel side workshops on ME/CFS at every Virology, Immunology, Neurology, Toxicology, and Genetics conference

Funding & education.
CFS is not a disease of the periphery.
Increase funding.
Increased funding.
Online educational videos. In person conference as well as online, CITI training, specific training from seasoned ME/CFS researchers, scientists, and physicians and other healthcare professionals including clinical research professionals. Certification. Offering points towards certification by watching informative videos like "Unrest" with Jennifer Brea as Mass General has done in Boston. Professor Ron Davis has shared his personal story of his son having very severe ME/CFS and bedbound, sharing this (Vimeo) will help spread more knowledge and awareness of the seriousness. Also, promote funding.
Work hand in hand with universities throughout the nation to establish grants for the research.
As above
-
/
No comment.
mentioned above

'ME/CFS' investigators are not needed. No other dual diseases are researched. Stop trying to pretend that ME and CFS are the same disease when the CDC itself found that they are not.

Start at the bottom and train doctors first. Training in Myalgic encephalomyelitis is sadly lacking. There are few experts and most are close to retiring.

Training is likely to take place in an existing team of investigators but unless such teams have secure ongoing funding, they cannot attract, train and supervise new investigators.

FUNDING

Apprenticeships with doctors highly experienced with this disorder. See Dr. Teich above. They may not publish or run clinics just for CFS/ME, but they know a lot about behavior and biochemistry.

There are branches who solely focus on a number of diseases. Create one for ME/CFS that is dedicated towards nothing but doing this work. It gives researchers a specific place to request funding and run their research. Too many of these projects are likely falling through the cracks due to lack of organization at NIH and lack of funding.

N/A

More money to the research centres so they can take on more post graduates

Education, funding and peer respect for being in a field that is making a demonstrable difference in QOL.

Afflicted celebrity endorsement people seem to respond to artists and performers of whom they hold in high regard (Lady Gaga, Cher, Morgan Freeman)

If you fund it, they will come.

Create an institute for CFS/ME research where ME/CFS researchers can contact each other and collaborate.

More testimonials from m.e sufferer's

Go to medical school and tell the story how m.e one of the most devastating illness has been ignored for 50 years

For all governments and public bodies to stand up and announce clearly this is the biggest mystery of our time and once solved will open the doors of many chronic illnesses. Put funding into understanding ME and PAINSS/PEM

I suggest you listen to the OMF foundation and the SMSCI organizations and listen to respected ME/CFS researchers, like Nancy Klimas, etc.

Wider dissemination of write-ups of recent meetings, such as the 4/19 NIH meeting. More training videos like the one at Bateman-Horne.

Raise awareness.

See all of the above - include a small bit of funding to aid showing Unrest at colleges et al.

They need to experience the disease and its devastating effects on patients' lives as a starting point so they can know what it is.

Again, isn't it obvious? Stop trying to discredit the disease, humiliate the patients and their medical helpers.

EDUCATION! ME/CFS affects vast swathes of the population worldwide, yet many doctors (even ones fresh out of medical school) have never heard of it or have a biased or limited view of the condition. We need to get everyone on the same page as quickly as possible.

Mandatory continuing education programs dealing with subject and more training to legitimize CFS starting in pre-med and on into internship for doctors. For researchers, more appeal to human compassion. It seems more people want to save the whales than us.

Medical education.

have it be collaborative across the various specialties (neuro, cardio, immune, etc)

Make it glamorous.

Highlight the economic burden.

Make visible the invisible - the bedridden and severely ill patient cohort.

Promote the growing discoveries in the field, along with the emerging technologies.

collaborate with environmental illness community

Recognition and titles for their position.

Increase funding. Connect interested researchers with mentors.

They should really see what patients lives are like. They need to talk to the patients and caregivers, and read what they've written. There should also be a totally free exchange of research data and ideas between researchers. This happens informally at the conventions but if they could give regular updates to each other, it might cause more collaboration. A monthly journal (print or online) for ME researchers would help.

These questions are all the same. They are not helpful to sick, saying people like me who live most of their lives from their bed.

Please consider us. You have the power to do good or evil.

Less delays in the system. People who maybe don't understand the illness should not be in charge of how research money is spent.

Funding

Integrate condition with immunology

More funding.

See above for career training.

More pre-conference seminars for young researchers.

Proactively funding PhD students to study ME/CFS, in many different academic fields.

Substantially increase funding by NIH and others.

Patients and their families should not have to fund this research. We need help now!

Interview patients

Watch Jennifer Brea's Sundance award-winning documentary *_Unrest_*, and likewise her TED talk on the subject, then become familiar with the history and current state of ME/CFS advocacy efforts online. Additionally, require as part of their training that each ME/CFS investigator observe or interact directly with individuals and their advocates/caretakers in both clinical and home settings, for the three levels of the disease (mild, moderate, severe). Ideally this would happen for both or multiple genders of patients, wherever possible. Include in-depth information about patient histories from a personal perspective, not just a clinical one.

- good quality international conferences

- ongoing research updates within the community of recent findings

- mentorship for career training

Funding.

Internships/residencies with known physician experts in the field.

Qualify the NIH conference(s) on ME/CFS for CMEs for clinician-researchers.

Create a curriculum for a college class seminar on MECFS, its history, efforts at treatment, and ongoing research, in partnership with the institutions of and or relevant researchers at the MECFS centers of excellence in Cornell, Harvard, and Columbia. This class outline can be made available freely online and can serve as an object lesson to potential doctors and researchers of the relationship between research, treatment, and society in a poorly understood disease. Two such versions of the course can be created: one which focuses on the biology and medicine while touching on the societal, gender, and economic issues of having a and this chronic illness, and one which focuses on the societal, gender, and Economic issues while touching on the biology and medicine. Creating both versions will widen the catchment population of those exposed to the disease, and the latter version can be rolled out sooner than the more biology focused one. The courses may best serve if they are outlines rather than whole courses: this will help professors engage with the material making it their own and will take up less resources.

Create a dedicated graduate fellowship/ scholarship position at each of the me/cfs centers of excellence so as to train researchers specializing in the field; creates opportunities for me/cfs centered research by students, even if students don't go on to specialize in this work after completion of their graduate or doctorate degree and they go on to work in another field they can expose other research fields and organizations to the research being done towards a cure for mecfs. Maybe funding can be got from not just independent organizations and the Department of health and human

services but found in the Education, and or Labor Departments' grants as these proposals relate to job training as well. These programs could be sponsored by private companies upon the agreement that recipients spend a certain number of post program years working at that company, or else forfeit what would essentially be corporate sponsored student debt forgiveness.

Money

I'd send them all to Cleveland's Center for Functional Medicine for training. Lifestyle variables are absolutely key to improving if you have CFS. Nothing I did early on helped until I did this, and then the results were astounding. Research in this area is a bit messy, but the results are real. It is an incredible gift to have my health back (well, its coming back slowly, this smart meter is such a heavy drain on my health. How can one have energy when their mitochondria are subject to constant pulsed wireless radiation all day? This is what actually happens if you bring an engineer in with a spectrum analyzer to look at the emissions of a smart meter using RF Mesh and a Zigbee, these are commonly used in Pennsylvania. Then there is the secondary issue of pulsed frequencies on the household wiring which also must be filtered out.

Standard definitions and criteria

The field will take off as adequate funding is provided and attention is drawn to the current ME literature. NIH members participating in the April Conference are well positioned to highlight this. The CDC and national neurology association leaders should also be enlisted since neurology played a major role in the dismissal of ME as a significant disease, relegating it to a psychological condition. Perhaps a neurological summit with the purpose of critically addressing this issue through a summit report. Dr. Koroshetz and Dr. Collins could co-lead this type of effort. It is unacceptable that leading neurology departments continue to advise patients to engage in exercise and cognitive behavioral therapy to the exclusion of medical treatment. Today, there are intriguing research developments that will offer career opportunities to researchers e.g., Dr. Jarred Younger's neuroinflammation research.

Recognize that the alleged "systemic exertion intolerance disease" (SEID) created by the 2015 IOM "ME/CFS" report is not ME and has been shown by independent research not to be a clinical entity. The CDC has misleadingly renamed SEID as "ME/CFS" but still defined by the IOM SEID criteria. See the MEadvocacy submission to NCHS regarding the recoding of CFS and the coding of SEID in ICD-10-CM for a detailed, referenced explanation why SEID (CDC ME/CFS) is not ME or a clinical entity. https://d3n8a8pro7vhm.cloudfront.net/meadvocacy/pages/22/attachments/original/1541437180/ICD-10-CM_Submission_Revised_Nov_2_2018.pdf?1541437180

Organize 'Vista' - type programs or forgiveness programs within every medical and related discipline to cover the loans and other validated educational debt of recent medical school graduates or indebted practicing physicians in exchange for working together and sharing research findings with each other at the COEs and the privately funded non-profit organizations. There should be publicly available clinics centrally located at each COE with experts in each discipline.

Create Continuing Medical Education (CME) programs that interest those new to the field.

Start by training at med schools, so that doctors know it's exists and is real.

As above.

Everything will always start with funding. Research cannot occur at all without any capital. I am aware that many ME/CFS experts periodically all travel to meetings and conferences to collectively discuss potential research paths and even more new theories (exosomes being the latest). However these researchers are limited by everything mentioned in all previous questions above, and often cannot take relevant action to quickly and effectively test any of these hypotheses or conduct very large scale studies of the smaller ones they may have done - smaller studies that hint at various components that might play pivotal roles in disease development and course. What is needed is the funding, resources, and ability to test each expert's theories in such a way so that the evidence or conclusions cannot be deemed faulty due to sample size or other problematic experimental design issues that could have been avoided if enough resources were available. It is unlikely that just one factor is singularly responsible for disease onset let alone persistent mechanism, therefore it must be necessary for all related researchers with hypotheses and data from all sub-fields to bring their individual puzzle pieces together. Ideally, this should help illuminate how several bodily systems and organs interact and work together in the first place even when functioning properly - an area that has never been very well explored (or of course, funded, because most research is aimed at specific illnesses or conditions and not general biological knowledge that underlies every single condition), and then of course help piece together how each component works off the others to initiate disease state. These researchers need the resources and support to each bring their sub-specialties to one another with conclusive data that sparks even newer ideas and perhaps novel treatments. I would also like to add that it is completely immoral and outrageous to have more interest and more bureaucratic support for things such as erectile dysfunction and plastic surgery procedures (from all applicable agencies) than for an illness affecting millions who are so incredibly ill that their QOL is worse than those with any single other ailment, which frequently leads to suicide due to lack of any respite from any available drug or procedure. The support and amount of time and effort the scientific community and the general population put into developing viagra and botox, when compared with something like amplitgen is highly discouraging for any researcher who is fully aware of the severity of ME/CFS and the need for any single reliable treatment. The NIH and FDA, as well as the media in general, need to put in some actual work with official outreach and education so that ME/CFS is seen as seriously as Lupus and MS, thus bringing public attention to how serious the disease is and how important these particular researchers are. Public support goes a long way; currently they have none. Nobody has ever even heard of this disease they are researching and putting their life's work into.

Career training should start in medical school with basic instruction in curriculum. Unfortunately, in a recent survey of 132 medical schools, only a third of them included ME/CFS in their curriculum. (Source: <https://tinyurl.com/y5u4cg2c>)

The study also pointed out that only a third of medical schools treated patients in a clinical setting, and 15% had research programs. When students are not exposed to information or given access to patients, it's difficult to attract young investigators or get them started on career paths.

<p>NIH Conference appears to be one way to deliver this i.e. allows researchers to learn about new approaches/areas. Also, the OMF approach of providing open access to data; in the case of NIH this (is/or?) could be via the shared ME facility.</p>
<p>Patient identification and diagnosis</p> <p>Physician and health care provider education</p> <p>Epidemiologists</p>
<p>Be more proactive on enlisting from FDA and other government entities, medical schools and scientific community. Old ways are not working and new ways need to be considered. Houston has one of the largest medical community's and research organizations in the country yet there's no ME/CFS research. Also involved medical associations and Boards in each state via the NIH to add continuing education courses</p>
<p>1) Offer supplemental funds to existing projects for components/spinoffs to be proposed and led by ECIs.</p> <p>2) Continue to offer ECI-targeted workshops and training opportunities, and travel support to conferences.</p>
<p>Must increase the funding to test hypotheses proposed by expert researchers.</p>
<p>See above.</p>
<p>Workforce development, programs/public campaigns to fight stigma even among healthcare workers</p>
<p>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!!!</p>
<p>Money and communication. Make ME become an attractive carrier path to med. students and excellent physicians. Make sure ME gets a higher status in the medical community worldwide.</p>
<p>-Provide doctoral and postdoctoral fellowships for ME/CFS research.</p> <p>-Fund an Academic Career Development Award program for ME/CFS researchers who want to enhance education. Bringing ME/CFS education into medical school programs will increase the number of medical students who know about the disease, potentially increasing the number who are interested in ME/CFS research as a career. In addition, more doctors knowledgeable about ME/CFS will not only help with the crisis in clinical care, but also provide a larger pool of diagnosed people for research studies.</p>

Medical school students must first receive enough education about this area to even know that ME/CFS exists!

Support the existing specialists to create a specialty or subspecialty and related association which would produce CMEs, educational conferences, best practice documents, literature reviews, a journal, and the like.

By being vocal about the reality of ME, researchers will no longer be dissuaded from joining the field. As it stands now there is still the perception that joining this field is "professional suicide". HHS, NIH and CDC can and MUST use all their power to change that narrative. News Media and Social Media MUST be used effectively to change this narrative. This is something ONLY HHS can do and this has been neglected for decades.

Again - make sure every researcher understands the different criteria and that the ICC patient group has been neglected in the conversation.

Give ME/CFS the same sense of urgency you've given to ebola, West nile virus, SARS, etc. It's destroyed a lot more lives. So if you were to do this, you would increase ME/CFS funding to be commensurate with its disease burden and could thus properly educate the medical community about it, and see that it gets taught in medical schools and there would be career opportunities because the funding would be there.

ME/CFS funding would have to be increased to at least \$235 million to gain parity with MS funding.

The lack of a reliable authority is problematic. There are many self-proclaimed experts, clinicians and researchers, in this disease who currently promote their own personal understanding, one that is completely at odds with reality. As a result, much of the available training is completely wrong, created by people who merely believe they understand the issue but actually promote misinformation.

As such, calling for more training will not be sufficient, as it is equally likely to be completely wrong as it is to be partially true at best. In the UK, the NHS provides formal training for GPs, unfortunately built on a wholly fictitious misrepresentation of the disease. More training is not sufficient, it has to be accurate and relevant.

The many myths that still dominate perception of ME need to be challenged before any large-scale training can occur and there has to be a legitimate authority that speaks with genuine experience and understanding.

The lack of genuine expertise is thus a serious obstacle, as most ME patients simply do not bother interacting with medical professionals, which only furthers entrenches the lack of clinical experience and awareness among clinicians. To train a new generation of clinicians, genuine experts are needed, yet they are far too few and a significant number of so-called experts are just as likely to misinform if they take on a training role.

This will not happen organically, as charlatans are just as likely to position themselves as experts, as has happened in the UK, Australia and elsewhere. There has to be a reliable and accountable

authority in order to provide a reliable foundation for large-scale training. This will only happen with strong patient engagement, which has yet to materialize anywhere.

* Spend at least one week in the life of a ME/CFS patient.

If I were an investigator, I would do precisely that. Patients have developed many strategies and tools for managing their disease; one of which may randomly lead to an important insight. Research success depends on random chance, but it is a strategic choice to increase the amount of relevant random encounters.

App/computer based education, Unrest screenings

MONEY MONEY MONEY. This brings talent in all fields if there is the promise of opportunity.

Educate at every opportunity of this field open to scientific understanding and exploration WITH FUNDING!!!!

Sponsor positions at NIH to work with a senior investigator in many of the institutes that involve the biological systems afflicted.

There could be a special fellowship program to which individuals who will perform ME/CFS postdoctoral research could apply.

Funding!

1. Maintaining the SEP (Special Emphasis Panel) for ME/CFS is important to assure researchers continue to get a fair, informed review of their grant submissions. It is not surprising that many grant reviewers from outside this field are ignorant or even hold misconceptions about the illness since they were not educated about it during their training and many scientific materials continue to be obsolete or inaccurate. If grant reviewers do come from outside the field -- and having them review ME/CFS grants may be beneficial for the field and them -- there should be some basic materials (e.g. NAM fact sheet, NIH reports) shared with them beforehand.

2. Mechanisms to provide funding for mid-career investigators to transition part of their work to this field would be helpful. Funding/ resources so they can take the time/ effort to learn more about the basics of this illness while applying their knowledge from other fields may be helpful.

Proper education is needed using the ICC definition and the International Consensus Primer (IC Primer) for all medical students, practitioners and researchers.

They should be trained on:

Myalgic encephalomyelitis: International Consensus Criteria -- 2011 research and clinical definition improving on the Canadian Consensus Criteria and distinguishing ME from CFS

<https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2796.2011.02428.x>

ME International Consensus Primer for Clinical Practitioners -- how to understand, diagnose and manage the symptoms of ME.

This primer is superior to information on the CDC website

https://d3n8a8pro7vhmx.cloudfront.net/meadvocacy/pages/2292/attachments/original/1554817421/Myalgic_Encephalomyelitis_International_Consensus_Primer_2012.pdf?1554817421

The false narrative that this is a syndrome of fatiguing conditions needs to stop now. It is the duty of HHS to properly educate medical professionals and the public about the disease ME.

At present there are no career training programs for ME/CFS researchers or specialists. And this may be considered two areas, training clinicians who see patients and training ME/CFS researchers.

Training clinicians would help people be diagnosed far sooner, many wait years or decades to get the diagnosis¹, which would help those patients who would be taught current knowledge of avoiding PEM episodes and prognosis. Those who were misdiagnosed could be referred to the appropriate specialists which may improve their outcomes as well. A higher and earlier rate of accurate diagnosis would also help create a larger cohort who might volunteer for research investigations and clinical trials when we get to that stage.

Training researchers on what they need to know to research ME/CFS, what the current knowledge is, and how to put their training and research interests to the best use if they go into ME/CFS research would not be difficult to come up with if the established players were approached. But before this can happen they need to have resources to do research themselves because they are working on the leads they already have with a severe lack of resources which they probably won't want to divert towards ends that will likely not pan out without institutional NIH support. A working group is a possibility for developing training materials.

¹<https://www.prohealth.com/library/a-profile-of-me-cfs-patients-how-many-years-and-how-many-doctors-25211>

(need to rest now)

Money!! Money!! Diagnostic marker brought to its conclusion and functional.

Funding levels of sufficient strength for people to consider devoting their lives to studying this disease.

Increase awareness of ME, its pervasive impact on patients' lives.

All healthcare and researcher education must include (accurate) training about ME. 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.

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?)

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.

Clinical Expertise (to increase # of accurately diagnosed patients thereby increasing the number of possible study participants)

- Creation of a central clinician/research organisation to do this as mentioned above.
- Use of online training materials and a credits based mechanism to encourage uptake.
- Frequent conferences and meetings for sharing knowledge.
- Publication of a regular Journal as the main output from the body

MEICC criteria

- Improvements and dissemination of knowledge in neuro-imaging, metabolomics, microbiome, mitochondria, exosomes, genetics, microRNAs, investment in big data analyses with computational researchers.

- Establishing best-practice protocols for obtaining and storing biological samples for future analysis by researchers

Funding!!!!

This is discussed on <http://www.me-ireland.com/training.htm>

-Many clinicians with expertise in this disorder are nearing retirement. There should be a formal mentorship program in which young medical students can shadow them. The NIH campus should accept MD-PhD students from nearby medical schools. Someone like Peter Rowe should get support for an MD-PhD student at Johns Hopkins. Don't make these busy clinicians apply, seek them out.

-There is a similar story with PhD researchers, with many getting older.

-The model of "we fund X percent of submissions, so submit more applications" does not work for this field. I cannot justify writing and submitting 5 grant proposals in order to get one.

-Offering a core curriculum for medical schools to use when introducing ME/CFS as a condition. For example, this could be an introduction followed by a series of case studies. The course could be in conjunction with other overlapping rheumatological conditions, such as fibromyalgia, Ehler's Danlos, POTS, etc. Furthermore, we believe it is of great importance for medical students to be exposed to this condition during clinical rotations, as it is not typically a condition present in hospitals. For example, in hospitals/institutions where this is possible, rewarding ME/CFS clinicians for mentoring MD students. Another example is through student-run clinics/initiatives. Student-run clinics are very popular at many medical schools. This opportunity could entail having first/second year MD students help with the administration of a ME/CFS clinician's office, thereby giving them experience in healthcare and exposure to this condition.

Research needs to be expanded mightily. With only 25 % of the symptoms shared and the balance personal, this will be difficult. There is a strong signal however, that advanced cases of ME present whenever the person has overdone it. It has been described by Whitney Dafoe (Dr. Davis' son) as a feeling like embarrassment- a feeling of pressure, perhaps heat, that occurs between the heart and the clavicle on every person I have met with severe ME. Some will not describe it like this, but it is the warning system of a crash. The more people interviewed and determined to have this reaction, the more solid subjects you will have for research. IN ADDITION, for career training, once it is established that we do indeed have this horrible disease in existence, then concentrate on OPEN MINDED medical

personal- people not entrenched to think that every woman with ME is nuts, and to realize that the men DO NOT TALK ABOUT IT. Group observation.

I think a 'centers of excellence' approach for ME/CFS research labs, including funding post-doc positions, would help strengthen researchers and bring more people into this area. But I also believe we should be working to attract experienced researchers from allied areas as well, to help with cross-fertilization of ideas. Also, choosing the 'centers of excellence' labs based on their competence in bio-informatics related to a systems biology approach would probably help ensure the new talent becomes competent in the most appropriate skill and knowledge areas.

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