

## Meeting the ME/CFS Medical Education Challenge

### Testimony for the Chronic Fatigue Syndrome Advisory Committee (CFSAC)

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ME/CFS presents a medical education challenge in the United States. [1] Perhaps because it is an illness diagnosed by a patient's report of symptoms, with variable pathophysiological findings among patients, and no known biomarker to support a diagnosis, many healthcare providers doubt a physical basis of the illness. The questioned etiology of ME/CFS in the minds of practicing physicians may discourage the inclusion of ME/CFS in medical school curricula. [2] But others factors, such as disproportionately lower research funding for this illness,[3] and the majority of research studies being statistically underpowered, [4] make curriculum development difficult. Recently, the credibility of some published data and their interpretation has been challenged, and the data only opened to public inspection after court order. [5]

The federal government has both directly and indirectly contributed to the lack of medical education and medical education materials.

The CDC, the federal agency charged with developing and providing medical education materials for healthcare providers in practice, has made three attempts to provide materials. None have increased the numbers of healthcare providers diagnosing and treating ME/CFS. The CDC's trained trainer program was withdrawn. [6] The CDC's *Spark Awareness Campaign*, included a *Healthcare Provider's Toolkit*; a pamphlet containing too little and inaccurate information. In June, 2012, the Chronic Fatigue Syndrome Advisory Committee recommended the U.S. Secretary of Health withdraw the Toolkit; an action supported by multiple ME/CFS patient organizations. [7] The more recent CDC diagnosis and treatment courses mounted on the internet have been tallied for the number of healthcare providers who have taken the courses and/ or the number of continuing healthcare provider education credits issued, but the impact of these courses on the numbers of healthcare providers subsequently diagnosing and treating ME/CFS was not measured. [8] A recent survey of 998 patients inquiring into their satisfaction with medical care found patients unable to access any care, patients unable to access specialized care, and a majority of patients being dissatisfied with the care when they receive it. [9] The CDC should be required to prove that their course curricula are effective. For ME/CFS courses to be effective, they need to: (1) increase the number of healthcare providers diagnosing and treating ME/CFS, and (2) increase the numbers of patients who receive and are satisfied with the care they receive.

The National Institutes of Health (NIH) has indirectly contributed to the paucity of medical education materials: (1) The NIH contributes to the false notion that ME/CFS is a woman's disease by placing its ME/CFS program in the Office of Research On Women's Health (ORWH). Placing ME/CFS in the ORWH implies that ME/CFS is an illness affecting only women. To the contrary, an estimated 1/3 to 1/4 of the adults who suffer from ME/CFS are men, and in children, the numbers of girls and boys

affected is equal. [10] Nevertheless, by implying that ME/CFS only affects a segment of the U.S. population, its importance and funding priority is lowered. (2) The failure of NIH to assign institute-directed, intramural research funds for ME/CFS, suggests that ME/CFS is unworthy of designated intramural research funding. Despite the fact that many illnesses which are less severe and affect far fewer Americans receive intramural, institute-directed, NIH funding, ME/CFS does not. (3) The NIH pays greater attention to illnesses that affect 200,000 or less patients through its Office of Rare Diseases Research (ORDR) than it does to ME/CFS despite ME/CFS affecting 10 times the number of patients than any of the rare diseases. [11] (4) The NIH disavows responsibility for ME/CFS education. The claim is that the NIH is a research institution and is not responsible for clinical education. Yet, one of the largest buildings on the NIH Bethesda campus is the Clinical Center through which many physicians pass to be trained. [12] Thus, the refusal of the NIH to support ME/CFS education, as in the ME/CFS Centers of Excellence because medical education is outside of its purview, is a specious argument.

Realizing the medical education challenges of ME/CFS, the CFSAC, established in 2003, formed an Education Subcommittee. In 2004, the Subcommittee wrote letters to both the American Medical Association (AMA), and the Association of American Medical Colleges (AAMC) requesting assistance in developing ME/CFS medical education materials. Neither organization responded. Several years later, an AAMC official would say during a chance encounter that in order to obtain a response from the AAMC, one would need to cultivate a friend inside the AAMC willing to work from within the organization.

The most successful and longest lasting medical education program to date within the United States is the ME/CFS Medical Scholar program conceived and sustained by the New Jersey Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Association (NJME/CFSA). Since 2006, NJME/CFSA has been providing medical education experiences to physicians in training. NJME/CFSA has targeted physicians in training because medical education is most effective when delivered to clinicians during their years of training. [13] In addition, physicians-in-training are less likely to have been exposed to, or to have developed negative attitudes toward ME/CFS from peers. The success of the NJME/CFSA program is apparent from its growth: Initially, restricted to medical students at one NJ medical school, and only to students between their first and second year of training, the current program encompasses all medical students and medical residents being trained in New Jersey. The program is a competitive. All aspiring ME/CFS Scholars are required to answer a specific essay question related to ME/CFS. Answers require extensive research and the reputable sources of information which form the basis of their answers must be listed in a concluding bibliography. A new question is generated every year. The applicant who writes the best scholarly paper answering the question asked is the ME/CFS Medical Scholar for the year. If the award winner is a medical student, s/he will receive a partial medical school tuition remission. If the award winner is a medical resident, a cash payment, to be used to pay down medical school debt will be issued. The award is presented at an appropriate medical school event at which the ME/CFS Medical Scholar explains the impact of the application process on his/her understanding of ME/CFS, and how the knowledge gained in the application process will impact his/her practice of medicine.

The reasons for success of the NJME/CFSA Medical Scholar Program have been recently articulated in a monograph published by the National Academies Press: (1) Healthcare providers should be provided with accurate information early in their professional careers, (2) The source of the education must be relevant and credible to the recipients. (Having a medical scholarship program within the medical school environment, chaired by a retired, medical school faculty member, fulfill these criteria.), and (3) The material presented should be developed to satisfy the interests of the intended audience. [13]

Expansion of the NJME/CFSA Medical Scholar Program into one or more similar programs should be considered. For example: (1) ME/CFS Medical Scholar programs could be developed in each of our 50 states, (2) One, national ME/CFS program could be established with one or multiple awards being given in each state,. (3) Were a ME/CFS Medical Scholar Program established with one ME/CFS Scholar declared in each state and a \$5,000 stipend awarded to each scholar, the direct cost of the program would be a modest \$250,000, (4) Were a national ME/CFS Medical Scholar Program established with one, large award, a \$50,000 stipend, or perhaps a \$100,000 could be awarded. Increasing the size of the award may encourage a larger number of applicants.

The NJME/CFSA Medical Scholar program demonstrates that ME/CFS healthcare-provider education is both feasible and sustainable. Moreover, the NJME/CFSA Medical Scholar program overcomes the recently articulated barriers of providing medical education for a stigmatized illness. Quite possibly, the lack of success of previous ME/CFS educational programs may in part be attributable to the failure of those programs to consider ME/CFS a stigmatized illness.

Hopefully, the information and suggestions contained herein will stimulate a long overdue, effective, national ME/CFS Medical Education program.

Respectfully submitted,

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[1] [Jason LA, Paavola E, Porter N, Morello ML](#). (2010) [Aust J Prim Health](#). 16(2):174-8. *Frequency and content analysis of chronic fatigue syndrome in medical text books*. After reviewing 119 medical text books, authors found ME/CFS content was presented on only 0.090% pages. Less prevalent illnesses were more frequently represented suggesting that the topic of CFS is underreported in published medical text books.

[2] Thomas, Marie A and Smith, Andrew P. 2005 *BMC Family Practice* 6:49. *Primary healthcare provision and Chronic Fatigue Syndrome: a survey of patients' and General Practitioners' beliefs*. Results of this study indicate that the level of specialist knowledge of ME/CFS in primary care remains low. Only half the general care practitioner respondents believed that the condition actually exists.

[3] Underwood, Emily (2015) <http://www.sciencemag.org/news/2015/08/lobbyists-seek-new-funds-chronic-fatigue-syndrome-research>. *Lobbyists seek new funds for chronic fatigue syndrome research*. #MEAction is asking for an increase in research funding comparable to illnesses with similar patient numbers and cost to society.

- [4] Beth Smith ME, Nelson HD, Haney E, et al.(2014) *Diagnosis and Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*. Rockville (MD): Agency for Healthcare Research and Quality (US); Dec. (Evidence Reports/Technology Assessments, No. 219.) Discussion. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK293934/> The main limitation of the evidence base in this review was poor study quality. Most studies were small and many were underpowered to detect significant differences.
- [5] Faulkner, George (August 19, 2016) <http://www.centreforwelfarereform.org/news/major-breaktn-pace-trial/00296.html>. *Major breakthrough on PACE trial*. "In a major breakthrough for people with ME/CFS a judge has rejected a university's £200,000 attempt to prevent release of data from the controversial medical trial, that was the first to receive DWP funding."
- [6] Brimmer, Dana J, McCleary, K. Kimberly, Lupton, Teresa A, Faryna, Katherine M, Hynes, Kevin and Reeves' William C. (2008) *BMC Med Educ*. 2008:49. (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2576246/>) *A train-the-trainer education and promotion program: chronic fatigue syndrome – a diagnostic and management challenge* "Qualitative and process evaluation data revealed that target audience and administrative barriers impacted secondary training feasibility."
- [7] MassCFIDS.org (September, 2012) <https://www.masscfids.org/advocacy/411-position-paper-to-cdc-on-cfs-toolkit-and-iacfsme-primer>. Position Paper to CDC on CFS Toolkit and IACFS/ME Primer. "On September 10, 2012, an alliance of ME/CFS patient organizations and independent advocates submitted a position paper to the CDC in support of the June 2012 CFSAC recommendation to remove the CFS Toolkit... Patients have expressed serious concerns with the content of the CDC CFS Toolkit because it fails to convey the seriousness of the disease, offers inadequate diagnostic guidance and even fails to acknowledge PEM as a hallmark symptom and focuses on CBT and GET for treatment."
- [8] Belay, Ermias. (May, 2013) CDC Report for CFSAC. (<https://www.hhs.gov/sites/default/files/advcomcfs/meetings/presentations/belay-052213.pdf>) *Results of the First Medscape Roundtable Spotlight CFS CME/CE*.
- [9] Sunnquist, M., Nicholson, L., Jason, L.A., & Friedman, K.J. (in press). . *Modern Clinical Medicine Research. Access to Medical Care for Individuals with Myalgic Encephalomyelitis and Chronic Fatigue Syndrome: A Call for Centers of Excellence*.
- [10] Jason, Leonard A., Barker , Kristen, and Brown, Abigail (Jan., 2012) *Rev Health Care*. 3(4): 257–270. ; Reyes M, Nisenbaum R, Hoaglin DC, Unger ER, Emmons C, Randall B, Stewart JA, Abbey S, Jones JF, Gantz N, Minden S, Reeves WC. (2003) *Arch Intern Med*. Jul 14;163(13):1530-6. *Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas*.
- [11] The NIH ORDR, "supports scientific conferences, a database of human biospecimen repositories, and research consortia of the Rare Diseases Clinical Research Network. ORDR works with many stakeholders within the rare disease community to accelerate the development of new therapies and diagnostic tools through programs like the Global Rare Diseases Registry." ([https://rarediseases.info.nih.gov/Files/GARD\\_brochure\\_English.pdf](https://rarediseases.info.nih.gov/Files/GARD_brochure_English.pdf))
- [12] CFSAC Recommendations and Agency Responses: August 18-19, 2015. Revised Responses Added March 8, 2016 Part 1: Recommendation from CFSAC's Patient Registry Working Group. Medical Education and Guidelines (#10-13). NIH's, "mission is to advance the science that then informs patients, caregivers and healthcare professionals... Its mission is to advance the science that then informs patients, caregivers and healthcare professionals."
- [13] Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change. Committee on the Science of Changing Behavior Health Social Norms; Board on Behavioral, Cognitive and Sensory Sciences; Division of Behavioral and Social Sciences and Education; National Academies of Sciences, Engineering, and Medicine, The National Academies Press, Washington, D.C., [www.nap.edu](http://www.nap.edu), 2016.

