Overview of ME/CFS

Myalgic encephalomyelitis (ME), commonly known as Chronic Fatigue Syndrome (CFS), is a complex, chronic disease with an array of debilitating symptoms ranging from a complete organ system shut down to extreme exhaustion, orthostatic intolerance (OI), unrefreshing sleep, joint pain, inflamed lymph nodes, sore throat, severe headaches, and many neurological abnormalities. The cause of ME/CFS is unknown and there is no existing cure nor FDA approved treatment. Patients experience a spectrum of symptoms and impairments. About 25% of patients are severe and incapable of basic functions like eating or bathing.

- The CDC has said that up to 2.5 million Americans have ME/CFS; Four times more women have ME/CFS than men
- People of all ages can develop ME/CFS; ME/CFS has been reported in patients younger than 10 and older than 80
- ME/CFS costs the U.S. up to $24 billion each year in direct medical costs and lost productivity – SOURCE: Institute of Medicine: “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness” Washington DC; National Academies Press, 2015 Feb 10
- Recovery is rare; symptoms often persist for life
- Patients with ME/CFS have the lowest median and mean quality of life scores of any disease tested, including lung cancer, rheumatoid arthritis, and brain stroke – SOURCE: The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome PLoS One. 2015; 10(7): e0132421. Published online 2015
- “There are now over 4,000 published studies that show underlying biological abnormalities in patients...It’s not an illness that people can simply imagine and it’s not a psychological illness.” – Dr. Anthony Komaroff, Harvard Medical School

Overview on ME/CFS Advocacy

For over 30 years, since the illness was first acknowledged by the CDC in 1985, advocates and scientists alike have fought an arduous battle for recognition and acceptance in the public consciousness and medical community. Like autism, ME/CFS has been the victim of bad science and horrible stigma; mislabeled as a psychological illness and mockingly called "yuppie-flu", and chronic fatigue syndrome. However, the recent publication of the Institute of Medicine (IOM) report “Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness” in 2015 has substantially shifted the ME/CFS landscape. The IOM report provided the much-needed official affirmation of the reality, prevalence, severity, and substantial government neglect ME/CFS has faced. (http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2015/MECFS/MECFS_ReportBrief.pdf)

Two organizations have come together in a strategic partnership to lead key segments of an hitherto divided but determined ME/CFS patient advocate community. Together, the Solve ME/CFS Initiative and #MEAction boast over 55,000 patient and caregiver contacts.

- The Solve ME/CFS Initiative (SMCI | www.solvecfs.org) was founded in 1987 and has established itself as the leading non-profit organization dedicated to ME/CFS. Our mission is to make ME/CFS widely understood, diagnosable, and treatable. Historically, SMCI is a research-centered organization, funding and conducting research, and seed grants to the fledging scientific field of ME/CFS. Just over a year ago, SMCI pivoted a portion of its focus to advocacy. The organization helped found the first nationwide ME/CFS Advocacy working group which is growing into a movement.

- In July 2015, the Myalgic Encephalomyelitis Action Network (#MEAction | www.meaction.net) launched its first beta website platform to mobilize a net-roots movement for patients who are too ill or housebound for traditional advocacy. #MEAction is an international network of patients empowering each other to fight for health equality for Myalgic Encephalomyelitis. Often described as the “Act-UP of ME/CFS,” #MEAction is the driving force behind the #MillionsMissing protest movement.
In the past year, this new coalition has:

1. Increased recognition by government and medical community including recognition of the Institute of Medicine report, supportive language in Senate appropriations committee report, successful advocacy for AHRQ addendum to previous report, recognition by NIH Director Collins and meetings with Acting Assistant Secretary of Health Dr. Karen DeSalvo.
2. Created advocacy unification among multiple ME/CFS groups and grassroots mobilization with online platforms
3. Bolstered an international effort to correct bad science – e.g. the PACE trial controversy and disease definition standards
4. Secured media recognition including TED Talks, local news patient profiles, and scientific developments featured in mainstream channels, and the upcoming release of major documentary film.

Several major ME/CFS advocacy and awareness events will be culminating this fall/winter. Carol Head of SMCI will attend the fall DC CFSAC committee meeting (not yet scheduled). From September through November 2016, an advertisement raising awareness about ME/CFS will be running in the heart of Times Square in New York City. On September 27th, the #MillionsMissing protest actions will take place with organized demonstrations in 21 cities worldwide. Jen Brea of #MEAction hosted a Ted Talk which is expected to be released in late November or early December in addition to the 2017 release of her documentary film “about ME and supported by the Sundance and Tribeca Film Institutes.

Federal Policy Changes Supported by SMCI

1. CDC - remove language and disease recommendations from their website and medical education programs that are based on bad science, resulting in treatment recommendations that have been shown to be harmful to patients – e.g. PACE Trial and Graded Exercise Therapy (GET)
2. NIH - publish the protocols of the NIH Clinical Center ME/CFS Intramural study for community input and follow-through on NIH Director Collins’ public commitments to “ramp up” funding and research. Publicly release the NIH extramural research plan for addressing ME/CFS which has been under development since October 2015.
3. Congress - allot $250 million in the budget specifically for ME/CFS, which is commensurate to the burden and prevalence of the disease when compared to other federal disease investments.

Where Congress Stands and Other Members of Congress

Currently, several actions regarding ME/CFS are gaining traction with members of the House and Senate. In the House of Representatives, California members Zoe Lofgren and Ana Eshoo are collaborating on a letter to NIH Director Francis Collins with additional support from Representative Barbara Lee. Lofgren and Eshoo had authored a similar letter in 2014 with the following co-signers: Sheila Jackson Lee (TX-18), Susan K. DelBene (WA-01), John Garamendi (CA-03), Eric Swalwell (CA-15), Michael M. Honda (CA-17), Daniel Lipinski (IL-03), Scott Peters (CA-52), John Lewis (GA-05), and Eleanor Holmes Norton (DC).

On the Senate side, the Senate Labor-H Appropriations subcommittee restored ME/CFS funding with strongly worded guidance in the committee report calling for several improvements including: NIH funding and a broad-reaching CDC medical education campaign. Senator John McCain (AZ) has committed to leading a series of actions on the Senate side.

How Members of Congress can help

1) Co-sign on to Representative Lofgren letter to NIH Director Collins; encourage other colleagues to sign-on as well.
   - Contact Angela Ebner, Legislative Assistant for Congresswoman Lofgren, at Angela.Ebiner@mail.house.gov or (202) 225-3072 to coordinate your participation.
2) Sponsor a House-side congressional briefing before the end of the year (target date, November 16th)
3) Put pressure on the CDC and NIH to take action
4) In the 115th Congress, assist in the creation of a bi-partisan ME/CFS caucus.

My illness is excruciating and difficult to cope with. It takes over your entire life and causes more suffering than I can describe.

Laura Hillenbrand, author of Seabiscuit and Unbroken, ME/CFS patient since 1987