2019-01 January Newsletter

Print

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Dear Friends,

Our year is off to a good start. We held a highly successful educational event for healthcare graduate students, healthcare professionals, and the public at the MGH Institute of Health Professions (IHP), our former President was a coauthor on a scientific paper, and we are gearing up for advocacy efforts in early April.

Educational Event for Health Care Providers on January 15th, 2019 - Huge Success!

This year's topic for the interprofessional rounds, a required class for MGH Institute of Health Professions (IHP) students, was "Invisible Disability: Providing Compassionate Care for a Person with ME/CFS." There were more than 650 people in attendance, including 600 students studying to be nurses, physicians assistants, physical therapists, occupational therapists, and speech therapists, as well as about 65 faculty, health care professionals and members of the public. The program included an excerpt from the movie "Unrest" and a panel discussion. Dr Ron Tompkins of MGH, Lisa Hall of Northampton Integrative Medicine, and patient representatives Rivka Solomon and Robie Robitaille participated in the panel. The audience listened with rapt attention, as evidenced by the extensive list of questions they submitted to the panel. The IHP published an article (https://www.mghihp.edu/students-hear-little-known-illness) about the event with links to a video of the panel and the presentation slides. Rivka wrote an article (http://www.prohealth.com/library/huge-event-held-mass-general-hospital-89607) that was published by ProHealth. This was certainly the largest ME/CFS event we helped organize and makes us hopeful for a future when health care professionals will be more knowledgable about this disease.

Research Article in Frontiers in Pediatrics

Our very own Charmian Proskauer, former President, was a coauthor on the article "Estimating Prevalence, Demographics, and Costs of ME/CFS Using Large Scale Medical Claims Data and Machine Learning (https://www.frontiersin.org/articles/10.3389/fped.2018.00412/full)," just published online in Frontiers in Pediatrics. This research looked at a large database of insurance claims (for nearly 50 million individuals) and estimated a prevalence of 0.5 to 1% based on use of the diagnostic codes for ME and CFS (ICD-10-CM). About 35 to 40% of the diagnosed individuals were men. The authors attempted to use a machine learning algorithm to identify patients based on symptoms. This approach worked for ME, arriving at a prevalence of 0.8%, similar to the diagnosed rate. However, this was unsuccessful for CFS, highlighting the facts that the category of CFS is not specific enough, and that the core symptom of post-exertional malaise does not exist as a symptom code. The take home message for patients is that if your doctor is able to make a diagnosis based on your symptoms, ask them to use the code for ME (G93.3) rather than the code for CFS (R53.82).

Upcoming Advocacy Events

Hampshire College will host a screening of Unrest on February 21. Ron Davis of Stanford will be on the panel along with his daughter Ashley Haugen, who is a Hampshire College alumna. The panel will also include Dr. Darren Lynch of Northampton Integrative Medicine and an advocate from our association. This screening and panel will be open the public -- everyone is welcome to attend!

Washington DC Lobby Day, organized by Solve ME/CFS and #MEAction, will take place on April 3. Anyone is welcome to travel to Washington for this big congressional advocacy event. You'll meet with your own representatives and/or their staff. If you plan to attend, register (https://lobbydayregistration.wufoo.com/forms/mxv6pqq161qoy5/) with Solve ME/CFS. If you are not able to travel to Washington, you can attend a meeting with your congressional representative by phone. Let us know if you are interested through our Contact Us (/contact-us-form) form. We are coordinating phone participation separately from Solve ME/CFS and #MEAction.

NIH Conference "Accelerating Research on ME/CFS (http://palladianpartners.cvent.com/events/accelerating-research-on-myalgic-encephalomyelitis-chronic-fatigue-syndrome-me-cfs-meeting/event-summary-2e5f90defaa4406e8fce234835e11fdf.aspx)" will take place April 4th and 5th on the NIH campus in Bethesda, MD. The conference is for researchers, but members of the public are welcome to attend and it will be videocast. If you want to attend in person, register here (https://palladianpartners.cvent.com/events/accelerating-research-on-myalgic-encephalomyelitis-chronic-fatigue-syndrome-me-cfs-meeting/registration-2e5f90defaa4406e8fce234835e11fdf.aspx?fqp=true).

Young Leaders Visualize Health Equity. The US National Academy of Medicine is sponsoring an art project on visualizing health equity. If you are between the ages of 5 and 26, you are invited to submit a piece of art (https://nam.edu/programs/culture-of-health/young-leaders-visualize-health-equity/?utm_source=National%20Academy%20of%20Medicine&utm_campaign=bf785d7ae0-Visualize%20Health%20Equity_COPY_03&utm_medium=email&utm_term=0_b8ba6f1aa1-bf785d7ae0-121555837) about your vision of a world where everyone has the same chance to be healthy, safe and happy. The submission deadline is February 28, 2019. Winners will be displayed in a virtual gallery and at a live gallery in summer 2019. This is a great opportunity to raise awareness about the impact of ME/CFS on young people.

We are always in search of more people to help with our activities. If you want to volunteer, please let us know through the Contact Us form on our website. And, of course, we always welcome finanical support for our activities in advocacy, education and patient services.

I hope your year is off to a good start,

Leah Williams, Association President