2019-11 November Newsletter

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Print

Dear Friend,

In this month's newsletter, a review of our annual event, congratulations to our local Ramsay Award winners, an appeal for the AMMES Financial Crisis Fund, a webinar on December 12, 2019, an announcement of the next Washington DC Lobby Day on April 21, 2020, and a reminder to download papers from the ME/CFS special issue. Read on for all the details. We wish you all a lovely Thanksgiving.

Annual Event Saturday, October 26th, Featuring Michael VanElzakker

Dr. Michael VanElzakker was our speaker at the annual meeting on October 26th. His topic was “Investigating ME/CFS at the intersection of the nervous and immune systems.” Seventy-five people attended the event at Newton Wellesley Hospital. The talk was very well received, and there were many interesting questions from the audience. Videos of Michael's talk and of the Question and Answer session are now posted on our YouTube channel here (https://www.youtube.com/watch?v=rIUccEITT6E&feature=youtu.be) and here (https://www.youtube.com/watch?v=IOnAkcue_Vk&feature=youtu.be).

At the membership meeting, we had an overview of recent activities, including a preview of the new strategic plan, and we elected two new members to the Board of Directors, Susan Buckley and Alyssa-Rae McGinn. Susan and Alyssa-Rae have been active volunteers over the last few years and we look forward to their contributions as Directors. At the member meeting, we also acknowledged our volunteers. Alyssa-Rae read special volunteer recognitions for Elizabeth (Libby) Potter for work with school nurses, Rivka Solomon for national advocacy, and Gaston Gingues (with Lisa Alioto) for social media work. All past volunteers were called to the front for a group photo (see below) and to receive “Massachusetts ME/CFS & FM Volunteer” pins in appreciation for their work. Thanks to Susan for this lovely idea and for ordering the pins.

Local Ramsay Award Winners!

We are very excited that two of the Solve ME/CFS Initiative (SMCI) Ramsay Award winners (https://solvecfs.org/smci-ramsay-grant-program/) are in Massachusetts. Michael vanElzakker, the featured speaker at our annual event, and Kenneth Kwong (both at Massachusetts General Hospital and Harvard Medical School) won funding for a project called "Brain perfusion changes in chronic fatigue syndrome before and after exercise challenge." Liisa Selin and Anna Gil (both at University of Massachusetts Medical School) won funding for a project called "Altered T cells in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)." In addition, newly arrived Massachusetts resident Amy Proal (of the Autoimmunity Research Foundation) is a collaborator on a third project called "Extensive characterization of the ME/CFS blood and CSF microbiome + virome." We look forward to hearing about the results of these projects. The Ramsay Awards (https://solvecfs.org/about-the-ramsay-grant-program/) are small grants intended to bring more researchers into the ME/CFS field, to enable researchers to collect preliminary data to support larger funding requests to NIH, and to promote cutting edge research.

Direct Support for Patients

As we all know, many people with ME/CFS are in desparate situations, unable to work or care for themselves, and often without the support of family or friends. There are many worthy non-profits in the ME/CFS community, but Erica Verillo's American ME/CFS and FM Society (AMMES) is the only one that provides direct support in the form of cash grants to stave off homelessness or starvation. If you are able, we encourage you to donate to the AMMES (https://ammes.org/) Financial Crisis Fund (https://ammes.org/ammes-financial-crisis-fund/) to support Erica's important work.

Upcoming Webinar: Thursday, December 12 at 1 pm ET

Our very own Charmian Proskauer, Past President, will be presenting a webinar in the SolveME Advances in ME/CFS Research and Clinical Series on “Estimating Prevalence, Demographics, and Costs of ME/CFS Using Large Scale Medical Claims Data and Machine Learning” on Thursday, December 12, 2019 at 10am PT // 1pm ET. Hope you can join. Register here: https://attendee.gotowebinar.com/register/5672391885160251405 (https://register.gotowebinar.com/register/5672391885160251405)

Mark Your Calendars: Advocacy Day is April 21, 2020

The 4th Annual ME/CFS Advocacy Week, sponsored by SMCI (https://solvecfs.org/), will take place from Sunday April 19, 2020 to Saturday April 25, 2020. The 2020 National Solve M.E. Advocacy Summit in Washington DC will take place from Monday, April 20 through Wednesday, April 22, 2020. The main event, ME/CFS Advocacy Day on Capitol Hill, will take place on Tuesday April 21, 2020 – where we hope to hold over 200 meetings with Members of Congress and their staff.

ME/CFS Advocacy Week brings people with ME/CFS, their loved ones, advocates, scientists, clinicians and caregivers from across the country together to demand more action and research funding, meet other advocates, and share their unique stories with members of congress, together in one voice.

For the latest information about the event, please visit the event webpage: http://lobby20.solvecfs.org (http://lobby20.solvecfs.org/). Registration (https://lobbydayregistration.wufoo.com/forms/r1cxni0m19b64lo) for Advocacy Day is now open. Participation is free, but you must register so that SMCI can arrange meetings with your congressional representatives. Participants are responsible for their own travel costs.

Reminder: View/Download/Post Papers from ME/CFS Special Issue!

Advances in ME/CFS Research and Clinical Care, a series of 25 papers on ME/CFS published in 2018-2019 in the online (open access, peer-reviewed) journals Frontiers in Neurology and Frontiers in Pediatrics, is in the running to win a $100,000 prize! The prize money must be used to fund a scientific conference on the topic. If it wins, the topic editors will donate the money to the IACFS/ME to help fund a future International conference! An important factor for winning the prize is the interest the topic generates around the world, based on article views and downloads, citations, and international reach. **We can help by viewing/downloading articles, and encouraging others to do so, especially viewers outside the U.S**. It also helps to post article links on Facebook or Twitter or Snapchat, retweet, and discuss in blogs and on Reddit. All these metrics are tracked and count toward the impact score.

For a complete list of papers with links, visit https://www.frontiersin.org/research-topics/7718/advances-in-mecfs-research-and-clinical-care#articles (https://www.frontiersin.org/research-topics/7718/advances-in-mecfs-research-and-clinical-care#articles). This special issue was edited by Drs. Kenneth Friedman, Cindy Bateman, Alison Bested and Zaher Nahle.

Volunteer with Us!

Can you help with our activities? We particularly need assistance with organizing events, revamping our website, and maintaining our database. If you would like to volunteer, please let us know through the Contact Us (/contact-us-form) form on our website. Or join our next volunteer phone call on Saturday, December 7 at 12 noon (Video & audio: https://zoom.us/j/395006189

(https://zoom.us/j/395006189); Audio only:+1 720 707 2699 US, Meeting ID: 395 006 189). And, of course, we always

welcome financial support for our work to improve healthcare and support services for people affected by ME/CFS. Warmly,
Leah Williams, Association President