Sharing the Success of ME/CFS Advocacy Week May 2017

This May, the events in Washington, DC marked the culmination of five months of planning as SMCI led two weeks of actions online, locally, and the Capitol building itself. In partnership with #MEAction, we built a national coalition to drive action in key areas of US policy and make the voices of people with ME/CFS heard in Washington, DC.

This monumental advocacy effort included actions for patients of every energy level and ability to participate, from a social media post, to a Capitol Hill face-to-face meeting with Congressional leaders. The goal of our efforts is to educate, empower, and deliver our message to Congress to take action on ME/CFS, and set the stage for 2018 advocacy. Our SMCI staffer Emily Taylor brings deep experience, having succeeded in similar advocacy for autism, prior to joining SMCI.

As part of ME/CFS Advocacy week, 52 ME/CFS advocates (composed ME/CFS patients and their loved ones) met with 712 members of congress and their representatives in Washington DC. Our efforts represented 56 states, districts, and territories from across the country. Additionally, over 25 local district meetings took place to supplement our Washington, DC-based efforts.

Effective advocacy is a slow, strategic, step by step process. With our eyes on the prize, our goal is to build foundations for sustained, effective policy work in the future. The most successful advocacy campaigns are layered with short term and long term goals folded together, with “easy” goals and more difficult long-term asks working together.

As one congressional staffer told our team, “we don’t fund by need, we fund by noise.” The Solve ME/CFS Initiative advocacy strategy in 2017 and beyond is specifically designed to make a lot of noise. And we need to make the right kind of noise in the right places; this is how experience strengthens our work.

DURING A TWO WEEK PERIOD IN MAY, WE SUCCESSFULLY COMPLETED, WITH #MEACTION:

- 71 meetings with Washington, DC congressional offices
- 8 meetings face-to-face with members of congress
- A sponsored Capitol Hill briefing with remarks from Senator Ed Markey (MA)
- 2 online actions resulting in over 3,327 messages to congress about ME/CFS
- 3 FREE online training webinars for ME/CFS advocates
- Over 25 local district meetings across the country
- A nationwide call-in day to members of congress
- Three successfully passed state resolutions on ME/CFS (thanks to Bobbi Ausubel, Mark Camenzind, and Laura Bucholtz)
- 1,161 advocates who took action on ME/CFS
- 6 tweets from politicians
Think Global – Act Local

The Solve ME/CFS Initiative was pleased to support many local advocates in securing proclamations from state and local governments acknowledging ME/CFS.

The State of California passed SCR 40 unanimously becoming the 6th state to pass an awareness resolution for ME/CFS. The California resolution led by Senator Steve Glazer and Assemblywoman Katherine Baker declared every May in California as ME/CFS Awareness Month. A special thank you to Marilyn Yu for leading the charge in Sacramento.

Local advocates Laura Bucholtz, Mark Camenzind, and Bobbi Ausubel led the charge in their home towns to pass three city proclamations for ME/CFS in Sarasota, FL, Palo Alto, CA and Walnut Creek, CA.

Winning Friends and Influencing Congress

In early August, the House Appropriations Subcommittee on Labor–HHS finally released their vision of federal spending for Fiscal Year 2018 in House Resolution 3358. We are disheartened to report that the accompanying committee report, again, zeroed out the $5.4 million line item for Chronic Fatigue Syndrome at the CDC’s Center for Emerging and Zoonotic Infectious Diseases.

Seeing this bad news for ME/CFS, within a week SMCI launched a nationwide action alert turn to the Senate to restore the funding for these critical research, education, and awareness programs. At the time of writing this piece, the congressional messaging campaign has resulted in approximately 1,850 messages to congress calling for the funding to be restored in the Senate bill.

Joining us in this campaign was one of the largest women’s organizations in the country, the National Organization for Women (N.O.W.). It was a significant victory for SMCI to collaborate with N.O.W. who stepped up to call out congress on their unjust and discriminatory treatment of ME/CFS.

Many thanks to Rivka Solomon and her mother Bobbi Ausubel for their work in making this happen.

The letter, signed by N.O.W. president Toni Van Pelt, urged congress “to seize this opportunity to quickly advance diagnosis, treatment, and a cure for ME/CFS, by restoring and expanding funding in research and education programs at a level commensurate with other similarly burdensome diseases unaffected by stigma or gender bias. Doing so will spur research at a time when many scientists believe that major discoveries are imminent, as well as bring new investigators into the field.”

SMCI welcomes N.O.W. as an ally and eagerly looks forward to more joint actions in the future for the millions of men AND women suffering with ME/CFS.