SMCI Continues Its Work to Drive Federal Action for ME/CFS

Looking Back at Advocacy in 2016

From the #MillionsMissing protest actions to the highest ranking ME/CFS policy meeting in history to the largest congressional action to date on myalgic encephalomyelitis, 2016 was a landmark year for ME/CFS advocacy. Below are some highlights of the 2016 advocacy work done by the Solve ME/CFS Initiative (SMCI):

- **THE BUDGET BATTLE** In February 2016, the President’s budget announcement included a bit of a shock: no funding for the Centers for Disease Control and Prevention’s ME/CFS multi-site clinical assessment. SMCI President Carol Head and other advocates from across the country traveled to Washington DC and successfully lobbied to have the $5.4 million budget reinstated.

- **SENATE COMMITTEE APPROPRIATIONS REPORT** Thanks to successful meetings on Capitol Hill, advocates secured strong language from the Senate Appropriations Committee to both the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC), directing these agencies to invest in ME/CFS research, include stakeholders as active participants, and work collaboratively to improve patient care.

- **#MILLIONSMISSING** On May 25 and September 27, #MEAction organized the two largest international actions for ME/CFS ever recorded. With 39 separate protests held around the world, thousands of patient activists made their voices heard. SMCI supported and spoke at protest actions on both days.

- **MEETINGS AT THE TOP OF HHS** Led by #MEAction, SMCI President Carol Head participated in two meetings with Dr. Karen DeSalvo, the assistant secretary for health at the Department of Health and Human Services (HHS). This may have been the highest level government official to meet with ME/CFS patients and advocates.

- **THE MIGHTY FIFTY-FIVE** U.S. Representatives Zoe Lofgren and Anna Eshoo of California led the charge by authoring a letter to NIH Director Dr. Francis Collins, urging him to continue strengthening the NIH’s efforts in ME/CFS biomedical research. An unprecedented 55 members of congress cosigned the ME/CFS letter, making it the largest congressional action on ME/CFS in recent memory.

- **MEETING AT THE TOP OF NIH** Carol Head and Dr. Zaher Nahle met with NIH Director Francis Collins in New York for a private conversation regarding ME/CFS.

Looking Ahead to Advocacy in 2017

SMCI is hitting the ground running. Guided by a new Policy Advocacy Statement, SMCI is committing to leading the charge on a number of major actions, including an ME/CFS Advocacy Week, an educational briefing on Capitol Hill, and a strategic push for the fiscal year 2018 appropriations cycle (10/1/17 – 9/30/18).

The first major advocacy event of 2017 was the annual meeting of the federal Chronic Fatigue Syndrome Advisory Committee (CFSAC) on January 12 and 13. SMCI holds a community liaison representative seat on the committee, and SMCI President Carol Head presented a strong
SMCI Continues Its Work to Drive Federal Action for ME/CFS (cont.)

vision of federal agency action on ME/CFS that included bolstering research investments, disability protections, ME/CFS patient equity, and medical education policies.

SMCI plans to support and boost this call for agency action with strong congressional support and advocacy mobilization. Key patient advocates are currently collaborating on a unified strategy with nationwide coalitions and key organizational partners. Following is a rundown of SMCI’s federal advocacy plans for the first half of 2017:

<table>
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<th>2017</th>
<th>JANUARY</th>
<th>FEBRUARY</th>
<th>MARCH</th>
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<td>CFSAC in-person meeting and presentation</td>
<td>Secure congressional support for Senate and House actions</td>
<td>Draft and send bipartisan appropriations letters</td>
<td>Advocate for ME/CFS to be included as part of Senate confirmation hearings</td>
<td>ME/CFS Advocacy Week to correspond with May 12 International Awareness Day for ME/CFS</td>
<td>Lobby for the creation of a congressional ME/CFS caucus</td>
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New Administration – New Opportunities?

Presidential transitions are turbulent affairs.

Thanks to the 2015 Presidential Transitions Improvements Act, the outgoing administration begins preparing for the incoming administration as early as May with a White House Transition Coordinating Council and an Agency Transition Directors Council.

In terms of ME/CFS advocacy efforts, the new administration presents potential opportunities. Nominees have been announced, and newly cultivated ME/CFS champions in the Senate stand ready to make our community needs part of the conversation. Potential new agency leadership, untainted by misconceptions or stigma about the disease, can lead to new opportunities to start fresh with an administration that has defined itself with a “getting business done” approach. At press time, current National Institutes of Health (NIH) director, and strong supporter of ME/CFS research, Dr. Francis Collins appeared to be a strong contender to remain in his leadership role, which would spell good news for the ME/CFS community. Dr. Collins has been one of the most effective directors to date in moving the internal processes of the NIH toward progress for ME/CFS.

However, the new administration also presents new challenges. The ME/CFS advocacy community has spent eight years cultivating agency relationships to make progress, and the potential to lose those small gains is very real. Furthermore, the nominee for secretary of the Department of Health and Human Services (HHS), Senator Tom Price, has spurned constituents with ME/CFS who have approached him in the past. SMCI will work actively with the incoming administration to educate and inspire action regarding ME/CFS.

Ultimately, it is not the administration that will dictate the future of ME/CFS, but advocacy. Working with strong coalitions, patient advocates, and congressional champions, SMCI stands ready to spearhead major actions for research investment. And that commitment will not waver.