

## **CFSAC TESTIMONY**

**Eileen Holderman - CFIDS Advocate**

**May 17, 2007**

Good afternoon to the members of the CFSAC Committee! My name is Eileen Holderman. I advocate on behalf of those with CFIDS. This week, I was on Capital Hill lobbying with the CFIDS Association of America. Because of my lobbying efforts, as well as my attendance at this Committee's meeting yesterday, and because of my own health considerations, I was physically unable to prepare my testimony for today. Therefore, I will present testimony in the form of an article that I wrote about my lobby efforts on Capital Hill two years ago.

Hopefully, my testimony will serve two purposes: one, to inspire advocates to continue in their endeavors to affect public policy to benefit the CFIDS community; and two, to establish a benchmark for all of us to gauge how the Federal Government has responded to advocates' past requests for action.

# American Voices in the Corridors of Congress

By: Eileen Holderman

For patients with Chronic Fatigue Immune Dysfunction Syndrome (CFIDS), getting heard is vital! That's why I took part in the CFIDS Association of America's annual Lobby Day event, held this year on May 12th, which coincided with International CFIDS/Fibromyalgia Awareness Day. About 60 advocates from across the country convened on Capitol Hill this past spring to voice concerns on behalf of the one million American men, women, and children contending with CFIDS.

As a Board of Trustee for the New Jersey Chronic Fatigue Syndrome Association (NJCFSA), I, along with fellow Trustee, Jackie Niederle, ventured to Washington, DC representing NJCFSA and Americans with Chronic Fatigue Syndrome (CFS)/CFIDS. Our association requested that I write an article about Lobby Day, 2005, to be published in the NJCFSA summer newsletter. My article was due last May - I missed the deadline. As a result, the editor asked me to submit the article for the fall edition of our newsletter and granted me three more extensions - all of which I missed. Presently, as I struggle to write this article, the editor is biting his nails, and I would venture to say, probably his lip as well, as I am single-handedly holding up the NJCFSA Newsletter that is distributed to 500 patients and medical professionals in New Jersey and around the country (Thank you, thank you, thank you - no applause, please!). Obviously, I am not only an advocate, but a CFIDS patient, too.

For patients with CFIDS (PWC's), deadlines can be deadly. The illness strikes nearly one million Americans of both genders, and all ages, races, and socio-economic brackets. The disease attacks all body systems but primarily adversely affects the immune, endocrine and central nervous systems. Symptoms include: cognitive and neurological problems, swollen lymph nodes, fever, sore throat, muscle and joint pain, gastrointestinal problems, sleep disorders, incapacitating fatigue, post-exertional malaise, dizziness, and many others. Despite countless abnormalities documented in clinical tests, there is no cure as yet, nor is there an effective treatment protocol for patients, many of whom are indefinitely disabled by the illness. As lobbyists for The CFIDS Association of America, one of our goals was to convey the seriousness of this illness to our Congressmen.

For inspiration, and to gear up to write this article, I slipped into my Levis blue jeans, Tommy Hilfiger American flag t-shirt, and my New York Yankees baseball cap (my signature head gear since age 2). Apparently, that triggered my sense of patriotism and the article began to materialize. As a proud Democrat and

American, I admittedly tear up whenever I hear someone sing, "God Bless America," often dress in patriotic colors, frequently crave apple pie, and value my right as an American citizen, to speak out on important issues. Each year, The CAA gives advocates the opportunity to exercise (forgive the word choice) that fundamental right.

The CFIDS Association of America (CAA) is a national organization dedicated to conquering CFIDS. Each year, the CAA hosts Lobby Day in Washington, DC. Advocates from across the United States of America, comprised of patients, caregivers, medical professionals and even researchers, join together for this annual event to ask our lawmakers for particular requests. There to train and prepare the advocates were President and CEO of The CFIDS Association of America, Kim McCleary, and her professional staff. Also there to assist were Tom Sheridan and his staffers of The Sheridan Group, a DC lobby firm. Day one of the event consisted of a training session that included review of written material and role-playing designed to prepare participants for their lobby sessions the following day on The Hill. Toward the conclusion of the training, advocates broke off into small groups of delegations representing the region of the US from whence they reside. Forming these groups gave the advocates an opportunity to get acquainted and formulate a plan for their meetings the next day.

As a veteran Lobby Day participant, I lobbied in the years past for the state of New York, but this year would be different. Though I was born and raised in New Jersey, I spent my junior high, high school and college years in Texas, after my family was transferred there as a result of my father's profession. Upon graduating from the University of Texas at Austin, with a degree in communications, I moved to New York City. For years, I worked in the media, as a radio broadcaster then went to work for a major art museum before being stricken with CFIDS. After living most of my life as a New Yorker, I recently returned to Texas. Despite my relocation, I remained affiliated with NJCFSA. Therefore, Lobby Day 2005 would be my first year to lobby for the state of Texas and I was the only participant representing The Lone Star State. Jackie Niederle, my fellow NJCFSA board member, lobbied for the state of New Jersey along with 5 other advocates from her home state.

When the training session ended, some advocates returned to their hotel rooms for much needed rest while others met for dinner with advocates from various parts of the country to network and discuss politics, public policy, health care, scientific research and funding.

The next morning, advocates gathered in the hotel lobby to meet their groups and ride together in taxis to Capitol Hill for their scheduled lobby sessions with their Congressmen. Unfortunately, some advocates were unable to make it down to the lobby because of post-exertional malaise - a defining symptom of the illness that strikes some patients immediately after physical or cognitive activity, rendering a patient unable to function; post-exertional malaise can also occur days or weeks

after activity causing set backs and relapses. Fortunately, The CAA considered the health needs of the participants by creating flexible schedules for their lobby sessions – allowing for pacing and resting and refreshments, arranging for staffers to lobby in lieu of advocates who couldn't due to health, providing wheelchair and disability access information, and accommodating advocates with discounted hotel rooms. The CAA also matched veteran lobbyists with newcomers so as to form a strong mentor support system. That morning, I was to lobby with Frank Campbell, a first time lobbyist from Colorado.

After I applied my under eye concealer to tone down the dark circles under my eyes from poor sleep quality, I put on my power pin stripe suit and gathered my agenda and went down to the lobby. There I spotted Frank, dressed in a suit and tie, holding a cane, waiting patiently for me. We hailed a cab and headed for Capitol Hill. Admittedly, Frank was justifiably apprehensive since our first meeting was to be with Senator Kay Bailey Hutchison, a Republican from Texas. When we were dropped off on Constitution Avenue, we looked around and were awed by the impressive sight: the beautiful Capital Building, the Senate and House buildings, the US Supreme Court and The Library of Congress buildings. We entered the Russell Building and had a meet and greet and photo-op with Senator Hutchison. Then we spoke with her staffers about CFIDS. Our first meeting went well and Frank settled into a natural, conversational style that assisted him in meetings he had throughout the day.

The CFIDS Association of America outlined our political agenda – breaking it down to four primary requests for our Congressmen:

1. We asked Congress to write a letter to the director of the National Institutes of Health (NIH), Elias Zerhouni, and tell him to issue a Request for Applications (RFA) for Chronic Fatigue Syndrome.
2. We asked Congress to support the creation of an office of trans-NIH initiatives by contacting members of the House Commerce Committee or Senate HELP committee.
3. We asked Congress to sign on to a letter to the Secretary of Health and Human Services (HHS), Michael Leavitt, implementing 11 recommendations from the Chronic Fatigue Syndrome Advisory Committee (CFSAC).
4. We asked Congress to contact members of the Labor/HHS Appropriations Subcommittee to tell them to increase the Centers for Disease Control and Prevention (CDC) fiscal year 2006 funding to 8.9 million for CFS.

Later in the day, Frank and I parted company as he went on to lobby for his home state and I continued, on my own, to appointments with my Texas representatives. If I happened to pass an office that had been responsive to the CFIDS community, such as Representative Nita Lowey, from New York, I would drop off a request

packet, in hopes of continued support. My best meeting that day was with the office of Texas Representative, Gene Green. I met with Congressman Green's Legislative Assistant, Lantie Ferguson. Ms. Ferguson was refreshingly real and bright and attentive. She asked great questions and gave assurances that Congressman Green would get briefed about our requests for CFIDS. Well, she must have been true to her word because Congressman Green signed on to the letter for Secretary Leavitt, along with about 12 others from Congress, including Representative Frank Pallone of New Jersey, who served as Democratic leader for signatures. The rewarding news of the Congressional letter sent to the Secretary of Health and Human Services was announced sometime after Lobby Day.

Following meetings on The Hill, Tom Sheridan invited all the Lobby Day participants to his lovely town house for a reception. Each year, Tom graciously hosts a post Lobby Day gathering to thank the advocates for their charitable efforts on behalf of the one million Americans with CFIDS. Though everyone was exhausted, most attended. My favorite part of the Lobby Day event is sinking down into one of the comfortable sofas at Tom's and chatting with the advocates. Some of the advocates were patients, holding themselves up with a cane or walker, fumbling over their words, but speaking with a new confidence and air of empowerment. Some advocates were wives who traveled across country because their husbands had CFIDS and could not speak for themselves and therefore acted as their spouse's spokesman. Some of the advocates were teenagers stricken with CFIDS, without the vocabulary of an adult, but courageous and willing to speak out as only a teenager knows how. Some of the advocates were doctors who treated CFIDS patients but never before spoke as an advocate for CFIDS patients. Some of the advocates were parents of children with CFIDS who spoke on behalf of their children because their voices were too young and faint to be heard. And some of the advocates were staffers of CFIDS organizations who spoke on behalf of those their organization represent, not out of obligation but out of an earnestness that developed from listening to the voices of those with CFIDS. All were the voices of advocates - all were the voices of Americans.

When Lobby Day concluded, all the advocates, especially the patients, returned to their homes to rest and recover. What lingered on for them was the hope that their voices were heard in the corridors of Congress.