



## What's Next in Our Advocacy Work?

It's late January as this is being written, and Capitol Hill is buzzing with change and challenge. President Obama is moving swiftly to name people to key positions in the Cabinet and federal agencies. Congress is taking up legislation left over from the session that ended before the holidays and putting new laws into the pipeline. Administrators for federal programs are finding ways to accommodate new leadership and priorities.

Looking to the year ahead on the CFS advocacy front, the Association will intensify its presence before the executive and legislative branches.

### **CFS advisory committee**

The federal CFS Advisory Committee (CFSAC) continues to be a critical forum for exchanging information and holding government agencies accountable for what they do (or don't do) for CFS.

At last fall's CFSAC meeting, held October 28-29, 2008, CFIDS Association President & CEO Kim McCleary presented searing testimony about funding improprieties in the U.S. Centers for Disease Control and Prevention's (CDC's) CFS research program. Association Scientific Director Dr. Suzanne

Vernon made an urgent plea for CDC and other federal agencies to better orchestrate studies and make data amassed with taxpayer funds more widely available to other researchers working in the field. You can read a comprehensive report on the two-day meeting, as well as testimony delivered, at [www.cfids.org/cfidslink/2008/110704.asp](http://www.cfids.org/cfidslink/2008/110704.asp).

### **CDC peer review**

Shortly after the CFSAC meeting, on November 5-7, 2008, the CDC hosted four outside researchers to conduct a peer review of the CDC's CFS research program. The report issued from this small group praised the CDC for its leadership in CFS research, but also drew attention to the lack of a "carefully articulated" five-year strategic plan for the agency's CFS program. This is a shortcoming that was also noted in peer reviews held in 1995 and 1998 and has been highlighted at several recent meetings of the CFSAC. The CDC is developing this plan now and intends to present it at the next CFSAC meeting, tentatively scheduled for May 28-29, 2009, in Washington, D.C.

Two other key weaknesses of the CDC's CFS research program were

identified as not engaging more external collaborators in their research and not having established any research networks with other scientists. In spite of promises made by the CDC, the reviewers were not asked to evaluate the CDC's existing contracts that have demonstrated a poor value for millions of dollars obligated by the agency. (See McCleary's testimony, referenced in the paragraph at left.) You can read the full review report at [http://cdc.gov/cfs/pdf/cdc\\_cfs\\_research\\_programexternal\\_review.pdf](http://cdc.gov/cfs/pdf/cdc_cfs_research_programexternal_review.pdf).

### **Funding cycle preview**

Another important venue for agency accountability will be the annual appropriations (funding) process that both houses of Congress begin in late winter. The House and the Senate both have subcommittees that initiate funding bills and directives for health and research spending. This year promises to be even more restrained, with bailout and stimulus packages consuming huge amounts of the federal budget (and increasing federal debt). But there are also some important initiatives anticipated, like the priority being given to health care reform, that should provide new opportunities to validate CFS and

**Looking to the year ahead on the CFS advocacy front, the CFIDS Association will intensify its presence before the executive and legislative branches of government.**



**NPR's Scott Simon**

**Online Bonus:** See videos of the May 8, 2008 Congressional Briefing on CFS. [www.cfids.org/cfidslink/2008/121004.asp](http://www.cfids.org/cfidslink/2008/121004.asp).

## New leadership will be coming to the CDC and the National Institutes of Health after a new secretary of health is confirmed by the Senate.

the needs of people whose lives have been diminished by it.

### DHHS briefing

We will continue seeking ways to get more of these needs addressed through federal programs—especially CFS research that is languishing at the federal level. New leadership will be coming to the CDC and the National Institutes of Health after a new secretary of health is confirmed by the Senate, and we are already staking a position to get CFS the attention its magnitude warrants. In fact, McCleary and Vernon will be briefing Wanda Jones, PhD, and her staff on February 24, 2009. Jones is a senior Department of Health and Human Services official now responsible for the CFSAC and communication with each of the federal health agencies' CFS programs.

### Staying involved

The Association will not conduct a lobby day this year due to the high cost of lodging in D.C. during the weeks Congress is in session and the effect of the economic strain on many members' personal finances. However, we will continue to explore ways to engage advocates through online tools like our Grassroots Action Center, local town hall meetings with legislators, and the local and district offices for U.S. senators and representatives. Sign up now to receive our free action alerts (see box at right). We'll continue reporting on our public policy work through our print and online publications. ■

### OCTOBER CFSAC MEETING SUMMARY

- 15th meeting of the CFSAC held Oct. 28-29, 2008.
- 8 of 11 members appointed by the secretary of health participated.
- Reports given by the CDC, NIH, FDA, HRSA and SSA.
- Extended discussion about concerns related to the CDC's research program followed the CDC report and public testimony from Association president & CEO Kim McCleary.
- Guest presentations covered proteomics of CFS, educational accommodations for CFS, legal issues faced by students, education of medical students and provider education outcomes.
- 17 members of the public delivered testimony.
- 5 recommendations were submitted to the secretary; disappointing was that none focused on research.
- Responsibility for the committee has now moved to the DHHS Office of Women's Health under Dr. Wanda Jones's leadership.
- Next meeting scheduled for May 2009.

Access a full meeting report and links to testimony at [www.cfids.org/cfidslink/2008/110704.asp](http://www.cfids.org/cfidslink/2008/110704.asp).



### Stay Informed. Exercise Your Power.

The Grassroots Action Center provides a quick and easy way to know what's happening on the CFS front and to make your voice heard in response. Enroll today at <http://capwiz.com/cfids/mlm/signup/>