

Educating the Medical Community

The national CFS public awareness campaign includes a number of initiatives to provide health care professionals with the tools they need to help CFS patients manage their illness. Those initiatives are already showing results, but we have a long way to go before compassionate and informed care is the norm.

BY MARCIA HARMON, DIRECTOR OF COMMUNICATIONS

The disbelief and skepticism that chronic fatigue syndrome (CFS) patients experience from family, friends and colleagues can be disheartening. But when that skepticism comes from the health care professionals whom patients seek out, desperately hoping for validation and treatment options, it can be devastating. And even when patients do manage to find a medical professional who believes CFS is real and who wants to help, the providers often don't know how to treat this complex illness.

The impact this has on patient health is one of the reasons that educating the health care community about CFS is a critical element of the CFIDS Association's mission. And it's why the Association has sought partnerships with the Centers for Disease Control and Prevention (CDC) to help educate health care providers nationwide. Since 2002 we have been collaborating with the CDC on

“Especially disappointing and disheartening have been the disbelief, skepticism and assumption that I’m psychologically impaired rather than physically impaired.”

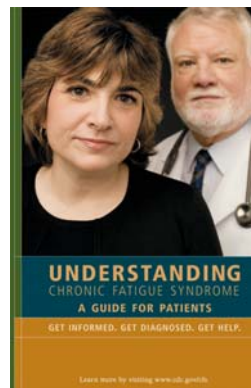
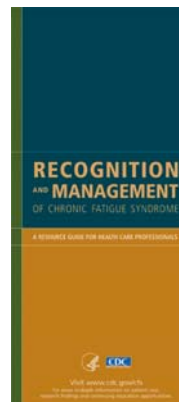
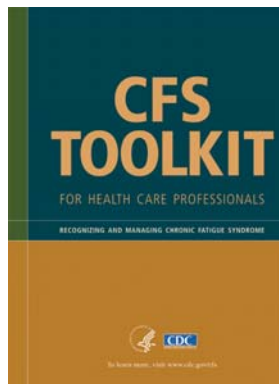
—ANNETTE PITTARI

In 2006, with the launch of the national CFS public awareness campaign, these provider education efforts were augmented. In fact, one of the main focuses of the awareness campaign is educational outreach to primary care professionals, including physicians, nurse practitioners and physician assistants.

Campaign educational resources

In addition to materials for the public and CFS patients, resources for the medical community were developed for the campaign. First, the content for the

the Provider Education Project, which offers two self-study courses for primary care and allied health professionals; conducts grand rounds and CME presentations on CFS at medical schools, universities and teaching hospitals; exhibits CFS educational tools at medical conferences across the country; and offers many other resources for the medical community.



section of the CDC’s website that covers CFS was overhauled to make it more user-friendly for both consumers and medical professionals and to bring it up to date. More than 1.2 million page views on this new “campaign microsite” at www.cdc.gov/cfs have already been recorded.

Next, the CFIDS Association and the CDC developed easy-to-use printed and downloadable resources. The campaign’s key provider resource is the *CFS Toolkit for Health Care Professionals*. In its downloadable format—available at www.cdc.gov/cfs and at www.cfids.org/cfs—this toolkit includes six fact sheets covering evidence-based approaches to the diagnosis and treatment of CFS. In its printed format—available only through the CFIDS Association—the toolkit includes a folder that not only holds the six fact sheets, but also includes a sample patient brochure for medical providers to copy for their CFS patients and a quick-read brochure, *Recognition and Management of Chronic Fatigue Syndrome*.

So far, more than 50,000 copies of these resources have been downloaded, distributed at medical conferences or mailed to health care providers who request them.

Strategic partnerships

The CDC and the CFIDS Association have been actively working on developing both formal and informal partnerships with

You can request that the Association send a toolkit to your health care providers by e-mailing meded@cfids.org with the names and mailing addresses of up to three medical providers. Talk to your providers first, so they’ll recognize the material when it arrives.

health care organizations. For example, we have formed alliances with the American Academy of Nurse Practitioners (AANP), American Academy of Physician Assistants (AAPA), Society for Women’s Health Research, American Academy of Family Physicians (AAFP) and other organizations to distribute educational information about CFS to their members.

Those alliances are already bearing fruit. The AANP has published three articles so far in its online journal, *AANP SmartBrief*, about CFS and the campaign resources developed for the medical community. The Society of Teachers of Family Medicine published an article in *STFM Messenger*, the official publication of this organization. And the American Academy of Pain Management published a story about the campaign and available resources in its online newsletter, *Currents*. Many other organizations have also done stories to educate their members, point them to the CDC website and provide links to the downloadable campaign resources for health providers.

Media coverage

The CFIDS Association and the CDC also invited many broadcast medical writers and journalists from leading medical journals to attend the press conference in November. Those contacts have led to numerous articles.

Christine Kilgore, who writes for International Medical News Group, attended the press event and wrote a piece for the December 2006 edition of *Internal Medicine News*, which reaches nearly 119,000 internists and physicians. The article frames CFS in a way that most doctors have



rarely seen. Kilgore quotes Dr. Julie Gerberding, the CDC director, who said, “Our strategy is to help patients know they require medical attention and to help clinicians be able to understand, diagnose and help patients . . . but most importantly, to be able to validate the disease and understand the incredible suffering.”

Kilgore goes on to quote Dr. Nancy Klimas, who refers clinicians to the campaign’s *CFS Toolkit for Health Care Professionals*, saying, “The CDC’s toolkit gives physicians ‘permission’ to do step-by-step symptom management rather than feeling as if they need to tackle it all and then being overwhelmed by time constraints and by the complexity of the illness.” (You can read this article at <http://www.internalmedicineneeds.com/article/PIIS1097869006745619/fulltext.>)

Susan Landers, a writer for the American Medical Association (AMA), also covered the story at the Association’s invitation. In an article for the November 27, 2006, issue of *American Medical News*, Landers not only reports on the basics of CFS, she also explores why an awareness campaign is needed. “After years of research, a critical mass of scientific data is providing solid evidence that CFS is a valid medical concern, said CDC Director Dr. Julie Gerberding, MD, MPH. . . . Thousands of research studies provide abundant evidence that CFS is a physiological illness, not a form of depression or hypochondriasis, according to the agency.” (A portion of this article is still available online at [http://www.ama-assn.org/amednews/2006/11/27/hlsb1127.htm.](http://www.ama-assn.org/amednews/2006/11/27/hlsb1127.htm))

Just this month the May issue of the *ACP Observer*, a publication of the American College of Physicians, covers CFS in an extensive article by Jessica Berthold titled, “Putting Chronic Fatigue Syndrome’s Myths to Bed.” After interviews with CFS experts Dr. Lucinda Bateman, Dr. Anthony Komaroff, Dr. Nancy Klimas and the CDC’s Dr. Suzanne Vernon, Berthold notes, “Respected researchers say it’s a condition that can be as disabling as AIDS or multiple sclerosis. Its prevalence is greater than that of ovarian cancer, lung cancer or lupus. And yet, nearly 20 years after chronic fatigue syndrome was officially recognized as a legitimate medical condition, many internists still doubt whether

it truly exists. The CDC is trying to change that.” (The full *ACP Observer* article is available at [http://www.acpoline.org/journals/news/may07/fatigue.htm.](http://www.acpoline.org/journals/news/may07/fatigue.htm))

This is just the tip of the proverbial iceberg. Some of the additional media coverage from health care organizations and from print, broadcast and online sources of medical news is noted in the box on page 29. Outreach continues, and more articles in the medical press are expected in the coming months.

“What amazing progress has been made in legitimizing CFS as a physiological illness! Today I saw a well-respected endocrinologist, and it was apparent he viewed CFS as a real illness. As he dictated notes about my postexertional malaise, it struck me that in the 1990s there was so much skepticism among almost all my doctors. I know I have the CFIDS Association to thank for this enormous progress.”

— F. WONG (April 2007)

“My husband has suffered from CFS for almost 20 years, and it’s great to see an organization like the **CDC finally telling the medical community that this is a real disease.**”

—JACKIE CONFALONE

Medical conferences

Campaign outreach to the medical community also includes exhibiting the traveling photo exhibit and campaign printed materials at various medical conferences. In 2006 the public awareness campaign was represented at the AAPA national conference in San Francisco, the AANP national conference in Dallas, the AAFP conference in Washington and at Pri-Med East in Boston. This year the exhibit schedule has already taken us to San Diego in April for the ACP conference. Next on the slate are the AAPA conference in Philadelphia and the AANP conference in Indianapolis.

These conferences give CFIDS Association staffers an opportunity to talk one-to-one with hundreds of medical professionals, many of whom have questions about how to handle CFS patients in their own practices. The exhibits also provide a point of dissemination for educational materials developed for the campaign, as well as the resources that are part of the Provider Education Project.

Much more work to do

It has been rewarding to hear from so many patients who think the tide may finally be turning within the medical community, with more acceptance of CFS as a real biologic illness and more willingness on the part of health care professionals to learn about CFS. But we also hear from patients who are still desperate to find compassionate, CFS-knowledgeable providers—and who are frustrated that more progress hasn’t been made.

The activities described here represent the early stages of campaign outreach to medical professionals, which will continue throughout 2007 and 2008. As the campaign continues to unfold, new activities will be added, more partnerships will be forged, more articles written, more materials disseminated and more understanding achieved. As Dr. Nancy Klimas so passionately declared at the press conference in November, “We need to educate health care workers about this illness until every doctor, nurse practitioner and physician assistant knows what the current standard of care and treatment strategies are for chronic fatigue syndrome.” ■

MEDICAL PRESS COVERAGE

The CFS awareness campaign has been widely reported on by the medical press and professional organizations. Some articles simply refer readers to campaign resources available to medical professionals, while others delve into the symptoms, diagnosis and treatment of CFS and are educational in nature. This list represents a small sampling of the coverage so far.

American Medical Association (AMA)

- *American Medical News* published “Campaign Puts a Spotlight on Chronic Fatigue Syndrome”
- *JAMA* published “Chronic Fatigue Syndrome Answers Sought” with a link to the toolkit

Society for Women’s Health Research

- Covered campaign in weekly e-newsletter

American Association of Retired People (AARP)

- AARP Broadcast News produced a video segment on CFS for national distribution

American Academy of Nurse Practitioners

- *AANP SmartBrief* published three articles on the campaign and CFS

WebMD

- Published “CDC: Chronic Fatigue Syndrome ‘Real’: Health Officials Call on Doctors and Public to Take Disease Seriously”

Age Management Medicine Group

- Published “Early Detection of CFS by Primary Care Physicians” in their *e-Journal of Age Management Medicine*

OB/GYN News

- Published article informing obstetricians and gynecologists about CFS and the campaign resources

Medical News Today

- Published “CDC Launches ‘Get Informed. Get Diagnosed. Get Help.’ Campaign”

Office on Women’s Health (DHHS)

- Published a campaign story in *Healthy Woman Today Newsletter*

American College of Physicians (ACP)

- Published “Putting Chronic Fatigue Syndrome Myths to Bed” in *ACP Observer*