

# THE CFIDS ASSOCIATION OF AMERICA

## May 12<sup>th</sup> - International CFIDS/CFS/ME Awareness Day 2007 Information Packet

Enclosed in this packet you will find:

- **Guidelines for May 12<sup>th</sup> Activities**  
How to get involved in advocacy, media and other efforts
- **Advocacy Information**  
CFS message points  
Information about the government's response to CFS  
Sample advocacy letter  
Key members of Congress
- **Media Information**  
How to get involved  
Message points for talking about CFS  
Additional media "tips"  
Suggestions for public awareness activities  
Sample media letter
- **Letter Writing Campaign Enclosure**  
Basic CFS Overview
- **Lobby Day Information**  
Please join us this year on May 14-15, 2007

**The CFIDS Association of America  
PO Box 220398  
Charlotte, NC 28222-0398**

**Resource Line: 704-365-2343  
Fax: 704-365-9755  
E-mail: [cfids@cfids.org](mailto:cfids@cfids.org)  
Website: <http://www.cfids.org>**

*Thank you for helping to increase awareness about CFS on  
May 12<sup>th</sup> - International CFIDS/CF/ME Awareness Day*

# GUIDELINES FOR MAY 12<sup>TH</sup>, INTERNATIONAL CFIDS/CFS/ME AWARENESS DAY

*PWCs, their families and friends are encouraged to educate others about the reality and seriousness of CFIDS on this day.*

## What Can You Do?

### Make your government representatives aware.

- Write, call or visit your Congressional representatives. If you don't know who they are or how to contact them, call your local voter registration office or League of Women Voters, the Capitol switchboard at 202-224-3121 or visit Web sites such as [www.congress.org](http://www.congress.org).
- Organize a support group member project!
  - Take copies of the enclosed advocacy letter to your support group meeting and write your letters together. Group members can either copy the letter by hand or use a photocopy of the enclosed letter. Remember, the sample letter can be used "as is" or as a guide for their own letters which can include more personalized information.
  - Make and bring copies of the enclosed CFS Fact Sheet, which explains what CFS/CFIDS is, who gets it and how it is managed.
  - Ask each group member to bring at least one envelope and one first-class stamp to the meeting.
  - Have each person place the letter and the CFS Fact Sheet in an addressed envelope, seal it, stamp it and then mail all the letters at once.

### If writing is difficult...

- Use the enclosed sample letter as-is.
- Ask someone to write the letter for you or dictate a letter to someone that you can sign.
- Make a phone call. *One phone call represents 150 others that support your issue.* Ask your U.S. Senators or Representative to support increased funding for CFS research. Call your Senators or Representative and ask to speak to the Health Legislative Aide (each member of congress has local offices in your state/district which may save you a long-distance phone call to their Washington, DC office). To find the phone numbers, look in the government pages of the local phone book or call the Capitol switchboard at 202-224-3121.

### Alert the media!

- Contact the health reporters at your local TV and radio stations, newspapers and magazines regarding CFS and Awareness Day 2007.
  - Mail your letters or call the reporters early. Program directors often plan ahead and since May is a TV and radio ratings "sweeps" month, they are busy preparing feature stories now for broadcast in May.
- Once you have a reporter interested in CFS, call Sara Collins, the Association's public relations and events manager at 704-364-0466, ext. 120 to request an information packet be sent to them.
- Designate someone as your group's spokesperson, so the media has a contact for stories.

### **Tell a friend or family member about what CFS really is.**

- Provide them with a free CFS Information Packet. To request a packet, call the Association's Resource Line at 704-365-2343.

### **Inform the general public.**

- Set up a display in your local library for the week of May 12 or the month of May. This can be done by the librarian with your suggestions for information to include in the display. The Association has several brochures suitable for these types of displays. For a list and cost, please call our Resource Line at 704-365-2343 or visit our Web site at [http://www.cfids.org/ecommerce/product\\_info.asp](http://www.cfids.org/ecommerce/product_info.asp). Please remember, this display does not need to be "manned" by someone from your group.
- Consider asking your place of worship to include a notice about the significance of May 12 in its worship material.
- Place a classified ad in your local newspaper or write a letter to the editor.

### **Educate a health care provider.**

- Give a health care provider a free Medical Information Packet from The CFIDS Association of America by calling 704-365-2343 and leaving his or her name and address.
- Download the CDC's Toolkit for Health care providers at <http://www.cfids.org/sparkcfs/tool-kit.pdf> and take it to your next appointment.

### **Remember...**

You don't have to do all of these things! Please DO try to write at least one letter to your Congressperson. Then if you're up to it, choose one of the other suggestions listed above (or come up with something new!) that suits you best and that you are best able to accomplish. Let us know what you are doing to make others more aware of CFS on May 12! Send your plans (and pictures) to The CFIDS Association of America, Attn: CFIDS Awareness Day by mail to PO Box 220398, Charlotte, NC 28222-0398 or by e-mail to [cfids@cfids.org](mailto:cfids@cfids.org). We will be doing an Awareness Day report in an upcoming issue of *The CFIDS Chronicle* and would like to include as many activities as possible.

***Thank you for helping to increase awareness about CFIDS!***

## HOW TO GET INVOLVED IN CFIDS ADVOCACY

In 1993, the CFIDS community identified May 12<sup>th</sup> as a day to make our government officials aware of the devastation caused by chronic fatigue syndrome (CFS, also known as chronic fatigue and immune dysfunction syndrome CFIDS). Help continue this tradition of awareness building by asking your Members of Congress to support increased and improved CFS research.

Here are some simple ways you can get involved in advocacy for Awareness Day:

- **Review the materials included in the advocacy section of this packet** and become familiar with the terms and language. You needn't master these requests. Although it's helpful to have many advocates echo the same message, your real goal is to depict the personal impact of CFIDS.
- **Find the names of your two U.S. Senators and one U.S. Representative.** There are several sources for this information, including the Capitol Switchboard (202-224-3121), your local voter registration office or League of Women Voters (look in your local phone book) and the Association's Grassroots Action Center at <http://capwiz.com/cfids/dbq/officials/>.
- **Contact your two Senators and one Representative.** And, if you're feeling up to it, please write to as many of the appropriators (listed on the next page) as possible, since they are the members of Congress directly responsible for health-related legislation.

You may photocopy and **use the enclosed sample letter** "as-is" by filling in the names and addresses of your three Congressional representatives (see below for proper format) and signing your name and writing your mailing address and phone number under "Sincerely" at the bottom of the page. Or, if you're up to it, **write an original letter**, as personal letters often get more attention from Members of Congress. Please review the Congressional Advocacy Message Points document and the Facts and Figures about the Government's Response to CFS document. Both will provide background when crafting your personal letter. You can use the sample letter included in this section as a starting point. The sample letter text can be copied from the Association's Web site at [www.cfids.org/advocacy/cfids-activists-smpl-ltrs.asp](http://www.cfids.org/advocacy/cfids-activists-smpl-ltrs.asp), rather than re-typing it.

Because mail is so slow to reach members of congress (for security reasons), you may find it more effective to send your message to Congress by fax, e-mail or telephone. You can link to all members of congress' websites at <http://capwiz.com/cfids/dbq/officials/>. If you choose to use fax or e-mail make sure to **include your postal mailing address** so the Member will know you are a constituent and will pay closer attention to your message. If you choose to use postal mail, please remember to include a return address on your envelope.

When addressing your letter, use the following formats:

**Senators:**

Honorable (Full Name)  
United States Senate  
Washington, DC 20510

**Representative:**

Honorable (Full Name)  
United States House of Representatives  
Washington, DC 20515

Dear Senator (Last Name):

Dear Representative (Last Name):

(Body of letter)

(Body of letter)

Sincerely,

Sincerely,

(Your name and mailing address)

(Your name and mailing address)

If you get a response from a member of Congress, please let us know. Send copies of letters and e-mail messages to The CFIDS Association of America, PO Box 220398, Charlotte, NC 28222-0398; fax 704-365-9755; or e-mail [cfidsadvocacy@cfids.org](mailto:cfidsadvocacy@cfids.org).

If the idea of becoming a CFIDS advocate seems overwhelming, don't worry. Even individual acts can help build support on Capitol Hill for the battle against CFIDS. Whatever your level of participation, you are building on the efforts of other advocates around the country to raise awareness and generate a more meaningful response to CFIDS from the federal government.

**Thank you for helping to build awareness of CFS  
among our nation's elected officials.**



# **ADVOCACY INFORMATION**

May 12<sup>th</sup> is  
International CFIDS/CFS/ME Awareness Day

# CFS MESSAGE POINTS

## **CFIDS Association of America Congressional Requests FY2008**

The CFIDS Association asks Congress to direct the **Department of Health and Human Services**, Office of the Secretary to prioritize strategies to address the low rate of diagnosis of CFS, lack of defined standards of medical care for CFS patients and the stagnation in research funding by CDC and NIH in spite of progress being demonstrated in the field.

The CFIDS Association asks Congress to express appreciation for the **National Institutes of Health** (NIH), Office of Research on Women's Health for its leadership on CFS research, particularly the coordination of the Request for Applications that culminated in the October 30, 2006 announcement of 7 new awards for CFS research. Congress should direct NIH to utilize the annual meeting of investigators funded under this initiative to stimulate new research initiatives and build multicenter collaborations that foster success under the Director's Roadmap Initiative. Congress should further direct NIH to develop an intramural CFS research program and to implement the recommendation made by the CFS Advisory Committee to "establish five Centers of Excellence within the United States that would effectively utilize state of the art knowledge concerning the diagnosis, clinical management, treatment and clinical research of persons with CFS." Congress should require that within 60 days of passage of the FY08 appropriations bill, that NIH report on how it will move forward on this recommendation and how it will address the erosion of NIH funding for CFS research. It should also remind NIH that it awaits the revised report on funding requested in the FY07 Appropriations Report, regarding the refined coding instructions for appropriately classifying CFS grants and insist that this be a priority for the newly established Office of Portfolio Analysis and Strategic Initiatives (OPASI).

The CFIDS Association asks Congress to commend the **Centers for Disease Control and Prevention** (CDC) for launching the first national CFS awareness campaign and the heightened attention being generated by these communications efforts conducted in collaboration with the CFIDS Association of America. In light of success so far, Congress should state that contract administration related to this campaign should not impede the progress nor slow precious momentum achieved so far in getting valuable information to the public and medical community. The Association asks Congress to acknowledge the work of the CDC's CFS research program, its systems biology approach to CFS and its global leadership. Congress should also recognize that this prominence and progress is jeopardized by the severe funding cuts reported for this program and express concern that funds are dropping even as CDC's own research indicates that the prevalence of CFS may be higher than previously documented, intensifying the need for expanded study and attention. The Association asks that Congress express concern that in FY07, report language provided \$1,000,000 over the budget request to protect the progress being made; however spending for CFS research for FY06 is estimated to reflect a 50% drop compared to the final spending figure for FY05. Congress should insist that CDC restore funding to the FY05 level of \$9 million and provide additional support to continue the effective public awareness campaign. Finally, Congress should indicate that it awaits the report from CDC on how the organizational restructuring will impact the CFS program as

well as a report on how CDC will address emerging evidence that human herpesvirus 6A and Epstein-Barr virus may play a role in CFS, perhaps as causative agents.

The CFIDS Association asks Congress to inform the **Health Resources and Services Administration** (HRSA) that the most crucial need for individuals suffering from chronic fatigue syndrome (CFS) is effective, compassionate medical care. Given HRSA's experience in piloting effective ways of delivering health care services to underserved populations and the statistic from CDC that fewer than 20% of patients with CFS have been diagnosed by a health care professional, Congress should encourage HRSA to announce a demonstration grant program to develop models for CFS clinical care with the goal of improving the diagnosis and management of individuals with CFS throughout our country. Congress should state that within 60 days of the passage of this bill, it requests a report from HRSA on how the needs of this population will be better met.

CDC researchers have reported that CFS is as disabling as chronic obstructive pulmonary disease, end-stage renal failure, and multiple sclerosis. In light of this finding, the CFIDS Association asks Congress to encourage **Social Security Administration** officials to continue the education of adjudicators at all levels about the functional impact of CFS to ensure that they remain up to date on the appropriate evaluation of disability that results from this condition. Congress should ask that within 60 days of the passage of this bill, SSA deliver a report on these ongoing educational activities as well any plans to update the existing policy ruling on CFS, SSR 99-2p.

The CFIDS Association asks Congress to request that the National Institute on Disability and Rehabilitation Research within the **Department of Education** continue to pursue CFS-related research proposals through its investigator-initiated and other grants programs, including sponsoring studies that will illuminate the nature of disability in CFS, particularly the predominant feature of post-exertional relapse, as well as strategies to support the improved function and rehabilitation of CFS patients.

## 2007 INFORMATION ABOUT THE GOVERNMENT'S RESPONSE TO CFIDS

The following is some background information about the government's CFS-related activities. You do *not* need to memorize these facts; a general familiarity with them will prepare you for meeting with your Congressional representatives.

### CFS Research

- In 1988, the Centers for Disease Control and Prevention (CDC) first defined and named "chronic fatigue syndrome" (CFS), which is also called chronic fatigue and immune dysfunction syndrome (CFIDS). In 1994 the definition was revised, and in 2004, CDC published some clarification guidelines to help further standardize patient classification for research.
- CDC and the National Institutes of Health (NIH) have each funded research investigating the prevalence of CFS in the U.S. Current estimates indicate that least one million Americans have strictly defined CFS. Estimates of "CFS-like" illness are much, much higher.
- CDC has studied the direct economic impact of CFS. Each year CFS costs our country \$9.1 billion in lost productivity. Adding medical costs and disability benefits push this number much higher. A researcher at DePaul University has developed an estimate of \$17-25 billion per year in combined direct and indirect costs due to CFS.
- Over 15 years, between 1990 and 2006, NIH and CDC invested about \$180 million in CFS research (\$95 million at CDC and \$85 million at NIH).

### Mixed Signals in Government Response

- NIH's CFS funds are at their lowest point since the mid-1990s.
  - The level of actual funding for 2005 was less than \$4 million. NIH reported a higher figure than this, but the CFIDS Association carefully analyzed their information and found that the figures were inflated by nearly 35% through the inclusion of studies that have nothing to do with CFS. A report documenting this is available from the CFIDS Association and has been presented to the government's CFS Advisory Committee and several Congressional appropriators and authorizers.
  - In July 2005, several institutes at NIH joined the Office of Research on Women's Health to announce a Request for Applications (RFA) for CFS with \$4 million in dedicated funds to support meritorious proposals. 37 proposals were received and funding for 7 new CFS projects was announced on October 30, 2006. However, this funding appears to simply replace grants that were set to expire and does not expand the total number of awards to support CFS research.
  - There are no centers funded by NIH where patients can participate in research studies and receive care. There is also no intramural research specific to CFS occurring on the NIH campus.

- CDC funds increased between 1999 and 2005, but have declined again, in spite of important progress and demonstrated productivity.
  - In May 1999, the Department of Health and Human Services Inspector General reported that between 1995 and 1998, CDC intentionally misrepresented to Congress the amount of money it had spent on CFS and more than half the funds — \$12.9 million of \$22.7 million — were actually spent to research other unrelated illnesses. Pressure from the Association, CFS advocates and Congress resulted in the CDC agreeing to restore the full \$12.9 million diverted from CFS. Initially CDC offered to restore just \$8.8 million to CFS research.
  - CDC has greatly expanded its internal research programs and has provided support to outside CFS researchers using the restored funds. It has moved from a focus on estimating prevalence to a broad-based program of clinical studies, lab studies, collaborative efforts and analysis of the impact of CFS as a major public health concern. The Association remains vigilant over the use of all federal funds.
  - Now that the “payback” period has ended, funding for CFS research has returned to the prior level of about \$6 million per year, jeopardizing the progress being made. In addition, CDC is reorganizing all of its programs and the destination of the CFS program is presently undetermined, although two meetings were held recently to make recommendations to the executive leadership about where the program fits best in the new structure. This potential move also puts progress at risk.
  
- The federal CFS Advisory Committee (CFSAC) began meeting in September 2003 and its charter was renewed in September 2005 for another two-year period. While the Department’s engagement with the Committee has improved in the past year, very few of the advisory recommendations have been implemented by the Department.

**Progress – now at risk!**

- CDC is utilizing cutting-edge technology to identify gene and protein activation markers that may lead to diagnostic markers for CFIDS.
  
- CDC is funding efforts to educate the public and health care professionals about CFS. The first CFS awareness campaign was publicly launched on November 3, 2006 at the National Press Club and has generated more than 1,500 articles/stories in the press about CFS.
  
- In July 2005, NIH released a Request for Applications (RFA). This RFA serves as a formal announcement to researchers that NIH is interested in funding CFS research. A committee of scientists met in January 2006 to review the 37 proposals that were submitted. Seven new CFS projects were funded and these grants were announced on October 30, 2006.

- The NIH Office of Research on Women's Health is responsible for managing and coordinating CFS programs at NIH. A Trans-NIH Working Group meets periodically to hear research presentations and discuss collaborative efforts that might benefit CFS. Now the recently passed NIH Reform Act of 2006 may result in changes to the structure of NIH that impact the Office of Research on Women's Health. Trans-NIH initiatives, like the one for CFS, need to be fostered and protected as changes are made to NIH's structure and organization.
- In April 1999, the Social Security Administration (SSA) responded to disparities in the handling of CFS claims by releasing a ruling on the proper adjudication of CFS-related cases. This ruling (SSR 99-2p) has improved CFS claims handling and tracking across the U.S., according to CFS patients, disability attorneys and SSA officials. SSA officials have indicated an interest in updating the ruling to reflect scientific advances, but no firm plans have been announced.

## SAMPLE ADVOCACY LETTER

Dear [Name of Elected Official]:

As one of your voting constituents, I am writing to ask for your help to increase research funding for chronic fatigue syndrome (CFS, also known as chronic fatigue and immune dysfunction syndrome or CFIDS). CFS affects more than a million American adults and teens, yet too few people understand its serious and long-lasting effects. It is characterized by severe exhaustion, disabling problems with memory and concentration, widespread muscle and joint pain and persistent flu-like symptoms. Research has documented defects in the brain and many body systems and new studies from CDC and other scientists indicate abnormal gene activity in several key regulatory systems throughout the body, but we still don't know what causes CFS or how to effectively treat it.

[insert a few sentences about why CFS is important to you]

In FY06, the federal government spent about \$14 million on CFS research and education. That's not enough, given the large number of people who have it, the \$9.1 billion annual cost to our economy and the severity of illness experienced by people during their most productive years. CDC has compared the level of disability caused by CFS to multiple sclerosis, end-stage renal failure and chronic obstructive pulmonary disease (COPD). There is no diagnostic test and treatment of the symptoms has limited effectiveness.

Please strengthen DHHS's CFS research programs by supporting the CFIDS Association of America's funding requests and recommendations for appropriations report language. You can view these recommendations <http://www.cfids.org/advocacy/cfsac-recommendations.pdf>, or get details from the CFIDS Association (704-365-2343).

I hope the more than one million Americans affected by CFIDS can count on your leadership and support. We are eager to return to healthy and productive lives.

Sincerely,

[Name and street address]

## KEY MEMBERS OF CONGRESS

After you write to your own Members of Congress, consider sending letters to as many of the following key Members of Congress as possible. Members of the House and Senate Appropriations committees are our top priority, as they determine health-related funding, but the House Commerce subcommittee and Senate HELP committee members listed below are key to our overall goals.

When writing to these Members, the first sentence of the sample letter on the next page will need to be changed, unless you are a constituent of the person to whom you are writing. Change the first sentence to: "As an American voter..."

## HOUSE OF REPRESENTATIVES

### APPROPRIATIONS COMMITTEE

SUBCOMMITTEE ON LABOR, HEALTH & HUMAN SERVICES, EDUCATION & RELATED AGENCIES (L/HHS)

#### MAJORITY

Dave Obey, Chairman (WI-7)  
Nita M. Lowey (NY-18)  
Rosa L. DeLauro (CT-3)  
Jesse L. Jackson, Jr. (IL-2)  
Patrick J. Kennedy (RI-1)  
Lucille Roybal-Allard (CA-34)  
Barbara Lee (CA-9)  
Tom Udall (NM-3)  
Michael Honda (CA-15)  
Betty McCollum (MN-4)  
Tim Ryan (OH-17)

#### MINORITY

James T. Walsh, Ranking Minority (NY-25)  
Ralph Regula (OH-16)  
John E. Peterson (PA-5)  
Dave Weldon (FL-15)  
Michael K. Simpson (ID-2)  
Dennis R. Rehberg (MT-at large)  
Jerry Lewis (CA-41), Ex Officio

## HOUSE OF REPRESENTATIVES

### ENERGY & COMMERCE COMMITTEE

SUBCOMMITTEE ON HEALTH

#### MAJORITY

Frank Pallone, Jr. (NJ-6), *Chairman*  
Henry A. Waxman (CA-30)  
Edolphus Towns (NY-10)  
Bart Gordon (TN-6)  
Anna Eshoo (CA-14)  
Gene Green (TX-29)  
Diana DeGettte (CO-1)  
Lois Capps (CA-23)  
Tom Allen (ME-1)  
Tammy Baldwin (WI-2)  
Eliot L. Engel (NY-17)  
Jan Schakowsky (IL-9)  
Hilda Solis (CA-32)  
Mike Ross (AR-4)  
Darlene Hooley (OR-5)  
Anthony D. Weiner (NY-9)  
Jim Matheson (UT-2)  
John Dingell, ex-officio (MI-15)

#### MINORITY

Nathan Deal (GA-10)  
Ralph M. Hall (TX-4)  
Charlie Norwood (GA-9)  
Barbara Cubin (WY-at large)  
John B. Shadegg (AZ-3)  
Steve Buyer (IN-4)  
Joseph R. Pitts (PA-16)  
Mary Bono (CA-45)  
Mike Ferguson (NJ-7)  
Mike Rogers (MI-8)  
Sue Myrick (NC-9)  
John Sullivan (OK-1)  
Tim Murphy (PA-18)  
Michael C. Burgess (TX-26)  
Joe Barton, ex-officio (TX-6)

## SENATE

### APPROPRIATIONS

SUBCOMMITTEE ON LABOR, HEALTH & HUMAN SERVICES, EDUCATION & RELATED AGENCIES  
(L/HHS)

#### MAJORITY

Tom Harkin (IA)  
Inouye (HI)  
Herb Kohl (WI)  
Patty Murray (WA)  
Mary Landrieu (LA)  
Dave Durbin (IL)  
Jack Reed (RI)  
Frank Lautenberg (NJ)

#### MINORITY

Arlen Specter, Ranking (PA)  
Thad Cochran (MS)  
Judd Gregg (VT)  
Larry Craig (ID)  
Kay Bailey Hutchison (TX)  
Ted Stevens (AK)  
Richard Shelby (AL)

## SENATE

### HEALTH, EDUCATION, LABOR AND PENSIONS (HELP) COMMITTEE

#### MAJORITY

Edward Kennedy (MA)  
Christopher Dodd (CT)  
Tom Harkin (IA)  
Barbara A. Mikulski (MD)  
Jeff Bingaman (NM)  
Patty Murray (WA)  
Jack Reed (RI)  
Hillary Rodham Clinton (NY)  
Barack Obama (IL)  
Bernard Sanders (I) (VT)  
Sherrod Brown (OH)

#### MINORITY

Michael B. Enzi (WY)  
Judd Gregg (NH)  
Lamar Alexander (TN)  
Richard Burr (NC)  
Johnny Isakson (GA)  
Lisa Murkowski (AK)  
Orrin G. Hatch (UT)  
Pat Roberts (KS)  
Wayne Allard (CO)  
Tom Coburn, M.D. (OK)



# MEDIA INFORMATION

Enlist the media's help in spreading the word about May 12<sup>th</sup>, International CFIDS/CFS/ME Awareness Day

## HOW TO GET INVOLVED IN CFS MEDIA OUTREACH

Approaching the media about covering CFS is an essential part of Awareness Day observances on May 12. Congresspeople often rely on media coverage as an indicator of their constituents' interests, and stories in their local newspapers and radio and television stations can help convince them that CFS is an issue worthy of their attention.

The CFIDS Association understands that people with CFS have limited energy and resources, and that developing relationships with local reporters is time-consuming. The materials provided in this section of the Awareness Day kit are designed to make media outreach as easy as possible. Here are some simple ways you can work with the media:

- **Review the media section of this kit**, particularly the message points. Consistency and clarity are very important when communicating with reporters, so become familiar with the Association's main messages. You don't need to memorize them, but they may be helpful in responding to reporters' questions.
- **Personalize and send the introductory letter.** Put your own finishing touches or personal information in the letter provided in the kit and send it to all of your local media along with the Basic CFS Overview. If personalizing, addressing and sending the letter is too energy-consuming, try asking friends or relatives to help. The letter can be used as-is by filling in the reporter/editor's name and signing in your name and writing your address and phone number under "Sincerely" at the bottom of the page. Once you have made the initial contact, we encourage you to call the Association's Resource Line at 704-365-2343 and request to have an information packet sent to the media contact.
- **Prepare for interviews.** In addition to becoming familiar with the Association's message points, think about what you want to communicate about your personal experience with CFS. Try to summarize it in a sentence or two, in case you only have a few minutes to get your point across in an interview. The more you practice delivering your summary verbally, the more comfortable and successful you'll be in getting your message across.

If you find that you're able to tackle more activities, consider the following:

- **Look for opportunities to write letters to the editor.** Letters to the editor normally respond to something you have read in a publication. Look for articles that can have special meaning for CFS patients. For instance, an article that talks about disabilities in general could give you an opportunity to write the editor about the specific challenges that patients and their families face.
- **Hold an event or other media opportunity.** May 12<sup>th</sup> Awareness Day is a good time to stage an event to gain media attention. For instance, you could arrange for a physician familiar with CFS to make a presentation at a local hospital or

other venue or set up an information booth at a local mall or library. Holding an educational event gives reporters an opportunity to add a visual element to the story via photographs or video footage.

You don't need to tackle all of these activities simultaneously. Do only what your health and energy level allow. If all of these activities are above your energy level, or you find you have time and experience to do even more, let us know. We'd be happy to make other suggestions. Whatever your level of participation, know that you're building on the efforts of other people with CFS around the country to increase public awareness about this illness.

If you'd like more specific information or help in deciding how to approach your local media, we encourage you to contact Sara Collins, the Association's public relations and events manager, by phone at 704-364-0466 or by e-mail at [scollins@cfids.org](mailto:scollins@cfids.org).

## MESSAGE POINTS FOR TALKING ABOUT CFS

Following are some points you may want to mention when speaking with reporters and other individuals about CFS. Message points help make sure the information the Association and its representatives provide is consistent and credible. You don't need to memorize these points verbatim, but they can provide an outline of what to emphasize.

- **CFS is more than just fatigue.** Chronic fatigue syndrome (CFS) is a serious, debilitating medical condition. In addition to severe fatigue, individuals with CFS experience problems with memory and concentration, pain in the muscles and joints, tender lymph nodes, headaches, postexertional malaise (prolonged, extreme exhaustion following physical or mental activity) and many other symptoms.
- **More than one million Americans have CFS.** This illness is not rare. In fact, CFS strikes more people in the U.S. than multiple sclerosis, lupus, lung cancer or ovarian cancer.
- **Less than 20 percent of Americans with CFS have been diagnosed.** More than 80 percent remain ill with little or no medical treatment. CFS is often misdiagnosed because it can mimic many other disorders, including multiple sclerosis, mononucleosis, chronic Lyme disease and lupus.
- **CFS strikes people of every age, ethnic origin and socioeconomic bracket.** Women are 4 times more likely to have CFS than men, and the illness is most common in people in their 40s and 50s. However, anyone can get CFS, including children. In this country CFS is at least as common among African Americans and Hispanics as it is among Caucasians.
- **CFS is a real medical condition.** There is no known cause or cure for CFS. However, scientists have identified numerous biological abnormalities in CFS patients. The director of the CDC, Dr. Julie Gerberding, recently declared that CFS is a real illness, and that it's a public health concern.
- **CFS is not psychological in origin.** Medical studies have proven CFS is not "all in the head," laziness or a mental disorder that can be cured with psychiatric treatment. Like sufferers of other chronic illnesses like MS and Parkinson's disease, some CFS patients become clinically depressed because of changes in brain chemistry and the debilitating nature of the symptoms, but depression is not the cause of CFS.
- **CFS can be treated.** Physicians can help improve a patient's quality of life by treating symptoms such as sleep disorders, pain and gastrointestinal difficulties. Drug therapy, physical therapy and lifestyle changes are often recommended. Graded activity and exercise can also help improve function when applied appropriately for many patients.

- **Exercise has to be redefined for CFS patients.** For CFS patients, learning to manage activity levels is key to managing the illness itself. This requires a new way of defining exercise. Although vigorous aerobic exercise is beneficial for many chronic illnesses, most CFS patients can't tolerate traditional exercise. Instead, CFS patients have to pace their activities and focus on balancing activity with rest to avoid a relapse.
- **The symptoms of CFS and the severity of the illness vary from patient to patient.** Symptoms vary from person to person in type, number and severity. Some patients are able to maintain fairly active lives. For others, CFS has profound effects on work, school and family life. People with CFS can be so ill that they can't complete the daily tasks of living, such as eating, showering or sitting up in bed. They may require a wheelchair or be completely bedbound.
- **CFS is an invisible illness.** Most people with the illness don't look sick. And those patients who are quite ill tend to only go to the grocery store, church, or other public places on days when they feel better than usual. The fact that CFS is invisible has contributed to misconceptions about the illness.
- **CFS can be disabling.** According to the Centers for Disease Control and Prevention (CDC), CFS can be as disabling as multiple sclerosis, rheumatoid arthritis, heart disease, end-stage renal disease, COPD and many other chronic conditions. The CDC found that 25% of CFS patients are disabled by the illness.
- **CFS has a severe economic impact.** A CDC study found that the annual economic impact of CFS in the U.S. is around \$9.1 billion in lost productivity, not counting medical costs or disability benefits. The average family affected by CFS loses \$20,000 a year in wages and earnings.

### OTHER THINGS TO KEEP IN MIND

- **Use the name chronic fatigue syndrome (CFS)** when talking about the illness to the general public and consumer-oriented media. The illness is also called chronic fatigue and immune dysfunction syndrome (CFIDS) and myalgic encephalomyelitis (ME), and switching between names can be very confusing for your audience. It's more effective to call the illness CFS for the sake of consistency and clarity in interviews.
- **CFS is not the same as chronic fatigue.** Chronic fatigue can be caused by lifestyle and overwork and by many different medical conditions, including cancer, anemia and diabetes. CFS, however, is a distinct illness with a specific set of symptoms that a patient must exhibit. There is a reliable diagnostic algorithm for CFS that differentiates it from simply being chronically fatigued.

- **The illness needs to be taken seriously.** CFS is often met with skepticism and the statement “I’m tired, too, so I must have it.” Calmly responding that they wouldn’t wish to have CFS since it’s so debilitating is a good response. Also, audiences sometimes interpret “there is no known cause or cure” as proof that the illness isn’t real. You can counteract this by emphasizing the major U.S. scientific powers—the National Institutes of Health and Centers for Disease Control and Prevention—believe CFS is a biologically based medical condition that can rob individuals of their ability to live normal lives.
- **When in doubt, refer to the Association.** If you feel uncomfortable answering a question about CFS, especially one about medical treatment or research, you can direct the individual to Sara Collins, the CFIDS Association’s public relations and events manager, at 704-364-0466 or [scollins@cfids.org](mailto:scollins@cfids.org). The Association will be able to answer or put the person in touch with an appropriate resource.
- **Make reporters aware of the national CFS public awareness campaign** sponsored by the Centers for Disease Control and Prevention and the CFIDS Association. Refer them to the Press Room section on the campaign website at <http://www.cfids.org/sparkcfs/press-room.asp> for information about the illness and the campaign.

## ADDITIONAL TIPS FOR DEALING WITH THE MEDIA

*This list provides some additional guidance on working with reporters to increase awareness of CFS and related disorders for CFIDS Awareness Day. If you would like more specific information or help in deciding how to approach your local media, please call Sara Collins, public relations and events manager, at 704-364-0466 or e-mail to [slcollins@cfids.org](mailto:slcollins@cfids.org).*

- **Use the materials and website created for the CFS public awareness campaign as resources.** You can visit our campaign website at [www.cfids.org/cfs](http://www.cfids.org/cfs) for information and downloadable resources, and you can feel free to refer the media to the website as well. You can also refer reporters to the CDC website at [www.cdc.gov/cfs](http://www.cdc.gov/cfs).
- **Be brief.** News stories require concise, succinct messages that can be easily converted into “sound bites” and short quotes. This is a good point to keep in mind when writing news releases or giving interviews.
- **Be “right.”** Contact the right reporter at the appropriate station or publication. For example, pitching a story about Awareness Day to a business editor, even if you know the person, may not be very helpful.
- **Be honest.** If you don’t know the answer to a question, such as an inquiry about a specific piece of CFS-related research, say so. Offer to find out for the reporter or refer him/her to the CFIDS Association of America.
- **Be prepared for questions.** You may need to provide information and answer questions in depth once you have a reporter’s interest. Think about how you will handle further inquiries in advance. You may want to check with a local CFS-knowledgeable physician to ask if he or she would be willing to be interviewed if a reporter wants to speak with a medical expert. Remember that you can always refer reporters to the CFIDS Association as well.
- **Assume everything is “on the record.”** It’s better to assume that the reporter will use everything you say, since there is no good way to ensure they won’t. So don’t say something in an interview that you don’t want to see in print or on the air.
- **Don’t do unusual things to “look sick” or “act sick” when interacting with the media or to cultivate sympathy.** Part of the message we want to convey is that CFS is an invisible illness to help combat the stigma about patients “faking it” or simply being too lazy to work since they don’t look sick.

## SUGGESTIONS FOR PUBLIC AWARENESS ACTIVITIES

*The guidelines at the front of the media packet list ways that you can alert the media, health care providers and the general public about CFS. Here are some additional ideas for increasing awareness, including a few suggestions that involve very little time and energy, for those who aren't physically able to tackle large projects. If you'd like more specific information or assistance, please call Sara Collins, public relations and events manager, at 704-364-0466, or e-mail to [slcollins@cfids.org](mailto:slcollins@cfids.org).*

- **Distribute flyers** at libraries, pharmacies, grocery stores, churches, pharmacies, health food stores and medical facilities (*Hint: if you don't have time to develop something new, simply distribute the Basic CFS Overview included in this packet. You might want to ask local youth groups to help deliver them.*)
- **Post information about Awareness Day** on your support group or local association's website, if you have one. Or you can contact local businesses, churches and other groups to see if they would include information or a brief notice on their sites.
- **Promote the public service announcements (PSA) that are part of the CFS public awareness campaign.** You can let local TV and radio stations know that there are new, professionally produced PSAs available. PSA directors at broadcast stations can download the PSAs from our website at <http://www.cfids.org/sparkcfs/tv-psa.asp> or they can request them from [media@cfids.org](mailto:media@cfids.org).
- **Give presentations on CFS** to church, women's, civic, school and youth groups. (*Hint: you could ask a local health care practitioner, friend or family member knowledgeable about CFS to present with you or give the presentation for you to help conserve your energy.*)
- **Conduct a "tell a friend" campaign** by asking support group members or groups of friends to pledge to educate at least three people unfamiliar with CFS before or on May 12.
- **Explore opportunities to partner with other local health groups** to spread the word about CFS and related illnesses. (*Hint: activities could include publishing information in each group's newsletter and joint educational displays.*)
- **Ask your health care providers to display information** in their offices for Awareness Day. Don't forget your dentist and optometrist. You can order brochures and other materials from the CFIDS Association (call the Resource Line at 704-365-2343 or visit [www.cfids.org](http://www.cfids.org) for suggestions), or you can photocopy the Basic CFS Overview included in this packet.
- **Leave information at local businesses.** Some companies have bulletin boards or allow health-related information to be left in their lunchrooms. You could ask friends and family to see if their workplaces would allow them to leave information about CFS for employees.

Dear

May 12, 2007, will be the 15<sup>th</sup> annual international CFIDS/CFS/ME Awareness Day. CFIDS, or chronic fatigue and immune dysfunction syndrome, is more commonly known as CFS, or chronic fatigue syndrome. To increase the general public's understanding of this debilitating illness, people around the world will be conducting CFS awareness activities on May 12<sup>th</sup>. Please help us educate health care consumers about this medical condition by reporting about CFS on or around May 12<sup>th</sup>.

A story on CFS would be especially timely now because the first-ever national CFS public awareness campaign was recently launched by the Centers for Disease Control and Prevention ([www.cdc.gov/cfs](http://www.cdc.gov/cfs)) and the CFIDS Association of America ([www.cfids.org/cfs](http://www.cfids.org/cfs)). In conjunction with this public health campaign, there are new materials for patients, the public and health care professionals. These materials include current, credible information about symptoms, diagnosis and treatment options.

CFS is a serious illness that can be as disabling as multiple sclerosis, lupus, heart disease and similar chronic conditions. CFS strikes more than one million Americans, but less than 20% have been diagnosed. Since early diagnosis and treatment can lead to better health outcomes for patients, it's important for Americans to know how to recognize the symptoms and where to find current, credible information about symptoms, diagnosis and treatment options. It's equally important for the medical community to become better informed about the illness.

The CFIDS Association has a Resource Line (704-365-2343) and a website ([www.cfids.org/cfs](http://www.cfids.org/cfs)) that you can include to give readers a way to request free information about CFS. You can also call the Association's media line at 704-364-0466 for more information or to request a press kit.

I believe that people in our community would be interested to learn about CFS. I would like to help you in any way I can with this project. Please contact me if you have any questions. I look forward to hearing from you and helping you create a very successful feature about CFS for your May health care coverage.

Sincerely,



# **LETTER WRITING CAMPAIGN ENCLOSURE**

Please include the attached general CFIDS Fact Sheet with each Awareness Day letter you and/or members of your support group send to members of Congress and media contacts.

# The CFIDS Association of America

*Working to conquer chronic fatigue and immune dysfunction syndrome*

## Basic CFS Overview

### CHRONIC FATIGUE SYNDROME

#### Who is at risk?

- Chronic fatigue syndrome (CFS) affects more than 1 million adults in the United States, and an unknown number of children.
- People of every age, gender, ethnicity and socioeconomic group can have CFS.
- CFS affects women at 4 times the rate of men.
- Research indicates that prevalence is highest in people aged 40-59.
- Although CFS is less common in children than in adults, children can develop the illness, particularly in adolescence.

#### What are the symptoms of CFS?

- CFS is characterized by medically or psychiatrically unexplained fatigue that lasts at least 6 months, that is not the result of ongoing exertion, that is not substantially relieved by rest and that causes a substantial reduction in daily activities.
- In addition to fatigue, CFS includes 4 or more characteristic symptoms: postexertional malaise (relapse of symptoms after physical or mental exertion); unrefreshing sleep; substantial impairment in memory/concentration; muscle pain; pain in multiple joints; headaches of a new type, pattern or severity; sore throat; and tender neck or armpit lymph nodes.
- Symptoms and their consequences can be severe. CFS can be as disabling as multiple sclerosis, lupus, rheumatoid arthritis, congestive heart failure and similar chronic conditions. Symptom severity varies from patient to patient.

#### How is CFS diagnosed?

- There are no physical signs that identify CFS.
- There are currently no diagnostic laboratory tests for CFS, so it's a diagnosis of exclusion.
- People who suffer the symptoms of CFS must be carefully evaluated by a physician because many treatable medical and psychiatric conditions are difficult to distinguish (for instance, mononucleosis, multiple sclerosis, various cancers, depression, bipolar disorder).
- Research conducted by the Centers for Disease Control and Prevention (CDC) indicates that less than 20% of CFS patients in this country have been diagnosed.

#### How is it treated?

- Since there is no known cure for CFS, treatment is aimed at symptom relief and improved function. A combination of drug and nondrug therapies is usually prescribed.
- No single therapy exists that helps all CFS patients.

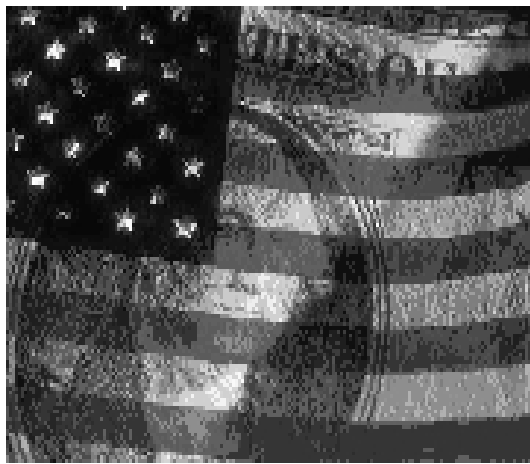
- Lifestyle changes, including prevention of overexertion, reduced stress, dietary restrictions, gentle stretching and nutritional supplementation, are frequently recommended.
- Carefully supervised physical therapy may also be part of treatment for CFS. However, CFS can be exacerbated by physical activity. A different approach to exercise and activity management is recommended to avoid overactivity and to prevent deconditioning.
- Although health professionals may hesitate to give patients a diagnosis of CFS for various reasons, it's important to receive an appropriate and accurate diagnosis to guide treatment and evaluation.
- Delays in diagnosis and treatment may be associated with poorer long-term outcomes. For example, the CDC's research has shown that those who have CFS for two years or less are more likely to improve. It's not known if early intervention is responsible for this more favorable outcome; however, the longer a person is ill before diagnosis, the more complicated the course of the illness appears to be.

#### Do CFS patients recover?

- CFS affects each individual differently. Some people with CFS remain homebound and others improve to the point that they can resume work and other activities, even though they continue to experience symptoms.
- Recovery rates for CFS are unclear. Improvement rates varied from 8% to 63% in a 2005 review of published studies, with a median of 40% of patients improving during follow-up. However, full recovery from CFS may be rare, with an average of only 5% to 10% sustaining total remission.

#### What causes CFS?

- Despite an intensive, nearly 20-year search, the cause of CFS remains unknown. Many different infectious agents, physiologic causes and psychological factors have been considered, and the search continues.
- CFS is not caused by depression, although the two illnesses often coexist. Many patients with CFS do not have any psychiatric disorder.
- Much of the ongoing research into a cause has centered on the roles the immune, endocrine and nervous systems may play in CFS. More recently, interactions among these factors are under evaluation.
- Genetic and environmental factors may play a role in developing and/or prolonging the illness, although more research is needed to confirm this. Researchers are applying cutting-edge genomic and proteomic tools to understand the origins and pathogenesis of CFS.



# **LOBBY DAY WASHINGTON, DC**

# Lend us your voice!

## Make your opinions count!

### Participate in CFIDS Lobby Day!

Recent CDC studies document that chronic fatigue and immune dysfunction syndrome (CFIDS) is as **disabling** as chronic pulmonary disease, osteoarthritis and severe depression, yet CFIDS is among the **lowest-funded** diseases by the federal government. By joining your voice with others, you can **fight more effectively** to increase the amount and quality of CFIDS research.

Plans for the CFIDS Association's **2007 Lobby Day** are under way. Make sure your congressional representatives hear the message about CFIDS—that it is **real**, it is **serious** and it warrants increased **attention and funding**—by participating in this year's event. Newly elected members of Congress, members of funding committees and representatives from your state need to understand the impact CFIDS has on their constituents and the communities they represent.

A mandatory training session on Monday afternoon, **May 14, 2007**, will prepare you to effectively share your CFIDS experience — or that of a friend or family member — with congressional staff members so they can share the message with congressional leaders.

On **Lobby Day**, Tuesday, **May 15**, we will work in state delegations to carry our message to the halls of Congress and into the offices of key legislative decision makers—the people who determine how much money federal health agencies will receive and what agency officials will be told Congress expects from them.

Please help to make your congressional representatives more responsive to CFIDS as an important public health concern by participating in Lobby Day 2007 in Washington, DC Full details and a registration form follow. For further information, contact the CFIDS Association of America (telephone: 704-365-2343; e-mail: LobbyDay@cfids.org, fax: 704-365-9755).

*"The 2006 event was my first Lobby Day, and it was my first time to be a lobbyist. I can't even begin to express how empowered I felt (and still feel) after this amazing experience. Thank you!"*

— Alyson Butcher  
Texas

*"I really am so grateful to the CFIDS Association for setting up the Lobby Day efforts. It has been empowering for me. The facts I've learned have made me a better advocate for myself on a day-to-day basis with friends and acquaintances."*

— Cheri Borsky  
Maryland

*"The most memorable aspect of Lobby Day 2006 was the time I spent (both in meetings and in between) with my group members. They were all wonderful people, so it was a joy to get to know them and work with them to send our message to our representatives in Congress.."*

— Hallie Kretsinger  
Kansas

# Lobby Day 2007 Details

Please join the CFIDS Association of America for the 2007 Washington, D.C. CFIDS Lobby Day Training and Capitol Hill Visits on Monday and Tuesday, May 14-15. To register, please complete and return the registration form by **Friday, April 20, 2007**.

We'll make appointments for you with members of Congress and staff and we'll train you to be an effective lobbyist — all you need to do is come!

If, for any reason, your plans to attend Lobby Day change, please let us know at the earliest possible date. We make appointments on Capitol Hill based on the individual participants and it is difficult to alter schedules to accommodate last-minute cancellations and no-shows. Thank you for keeping this in mind as the date approaches.

## ***Dates & Information to Remember***

<b>Friday, April 20</b>	<b>Deadline for making hotel reservations at the Washington Plaza</b> (see below)
<b>Friday, April 20</b>	<b>Registration form due at the CFIDS Association of America</b> Your timely response helps us better utilize your time while in D.C.
<b>Friday, April 27</b>	<b>Preparation materials mailed to all Lobby Day participants</b>
<b>Monday, May 14</b> 1:00-5:00 pm	<b>Mandatory Lobby Day Training Session</b> Washington Plaza Hotel, 10 Thomas Circle NW, Washington D.C.
<b>Tuesday, May 15</b> All Day	<b>Capitol Hill Visits (Lobby Day)</b> Schedules will be distributed at the afternoon training session. <i>Please do not make your own appointments -- we will contact members of Congress on your behalf to arrange meetings.</i>
5:30 pm	<b>Lobby Day Wrap-Up Party</b> Lobby Day participants are invited to a post-Lobby Day celebration at Tom Sheridan's home to share the day's experiences and achievements.

## ***Hotel Information***

***Washington Plaza Hotel***  
***10 Thomas Circle, NW, Washington, DC 20005***  
***Phone: 202-842-1300 or 1-800-424-1140***

Group rate reservations **must** be made **by 5:00 pm on April 20**. Room rate: \$149 (plus tax) per night.

**Reserve your room today, either by phone or online!**

\*Call in your reservation locally at 202-842-1300, or out of state at 1-800-424-1140, ***mention group code "CFIDS-Lobby Day" to get the group rate*** and provide a credit card number to guarantee your room.

\*Book your reservation online at [www.washingtonplazahotel.com](http://www.washingtonplazahotel.com) – click on MAKE A RESERVATION, then click "Group Reservations" at the bottom of the screen. Enter the "Attendee Code" # 5961 and you will see the CFIDS Association's group information, continue the process to make your reservation.

# 2007 Lobby Day Registration Form

Please note: We will be scheduling meetings with members of Congress on behalf of participants, so having an accurate list of attendees is important. Since illness and other complications sometimes result in unexpected cancellations, we ask that you notify us at the earliest opportunity if you, or someone you have registered, will not be able to attend. Registration deadline: April 20, 2007.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City/State/Zip: \_\_\_\_\_

Telephone: \_\_\_\_\_

E-mail (if applicable): \_\_\_\_\_

I am:  a person with CFIDS  a family member or friend  other \_\_\_\_\_

Yes, I would like a complimentary "Spark!CFS" T-shirt. My adult T-Shirt size is \_\_\_\_\_

## In Washington, I will be staying:

At the Washington Plaza (call **202-842-1300** or **800-424-1140** — by April 20: code "CFIDS-Lobby Day")

At home or other accommodations:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Local phone: \_\_\_\_\_

## Special needs (please check all that apply):

I will be participating in a wheelchair and will bring someone to help me get around.

I will be participating in a wheelchair and need a person to push my chair. (While we try to recruit healthy volunteers to push wheelchairs, *there is no guarantee that we will have enough helpers for everyone*. If you plan to use a wheelchair, please try to bring an able friend or relative to help.)

Other: \_\_\_\_\_

## Meeting preferences and information:

Each meeting typically lasts 10 to 20 minutes. We will assign appointments based on advocates' home states and congressional committee assignments. *Please do not schedule your own appointments*. We will try to accommodate your preferences (noted below), but we can't guarantee them, as we are dependent upon the availability of congressional members and staffers on May 15.

## Please schedule me on May 15 for (please check all that apply):

Morning appointments on Capitol Hill

Afternoon appointments on Capitol Hill

A maximum of 3 meetings (light schedule)

A maximum of 9 meetings (heavy schedule)

In addition to my home state, I have personal connections and would be willing to meet with Congresspersons from the following state(s) (if needed):

State: \_\_\_\_\_ Connection: \_\_\_\_\_

State: \_\_\_\_\_ Connection: \_\_\_\_\_

(continued)

**The following CFIDS advocate(s) will be attending with me:**

Name: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

City/State/ZIP: \_\_\_\_\_

Telephone: \_\_\_\_\_ E-mail (if applicable): \_\_\_\_\_

This person is:  a person with CFIDS  a healthy family member or friend  other \_\_\_\_\_

Name: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

City/State/ZIP: \_\_\_\_\_

Telephone: \_\_\_\_\_ E-mail (if applicable): \_\_\_\_\_

This person is:  a person with CFIDS  a healthy family member or friend  other \_\_\_\_\_

**Please complete and return this registration form to Kim Almond's attention  
no later than Friday, April 20, 2007 using the mailing address or fax number below.**

The CFIDS Association of America, Inc. • 6827 Fairview Road, Suite A, Charlotte, NC 28210  
Phone: 704-365-2343 • Fax: 704-365-9755 • E-mail: LobbyDay@cfids.org

### **Additional Information**

#### **Media contacts**

Media in your local community may take an interest in your participation in the Association's Lobby Day activities. Your plans to attend this event might also be the "hook" that interests a reporter in writing a story about CFIDS and how it impacts a local resident. This year we'll use the Association's on-line Grassroots Action Center (GAC) to contact newspaper, radio and tv reporters. In late April, we'll contact you by e-mail with specific, easy-to-follow instructions on how to spread the word that you're headed to Washington, D.C. to educate lawmakers about CFIDS. You'll be able to determine how you wish to portray your own story and which media outlets receive the information. If you haven't used the GAC before, visit it now to see for yourself how easy it is to use – go to [www.cfids.org](http://www.cfids.org) and click on the Capitol Building icon. You can also sign up to receive periodic notices about issues of potential interest and opportunities to make a timely impact on lawmakers and public health officials.

#### **Air travel to Washington, D.C.**

Airlines service the Washington area through three airports: Reagan National (DCA) (the closest to downtown D.C.), Dulles International (IAD) (located west of Washington, D.C. in Virginia) and Baltimore-Washington (BWI) (located close to Baltimore, MD). While travel in and out of Reagan is the most convenient, fares are sometimes more attractive using Dulles or BWI. You can search all 3 airports at once on [expedia.com](http://expedia.com) or [Travelocity.com](http://Travelocity.com) using the WAS code. Southwest Airlines has a large number of flights to/from BWI; check their schedule and fares at [www.southwest.com](http://www.southwest.com).

Other travel details will be included with preparation materials.