

# THE CFIDS ASSOCIATION OF AMERICA

## May 12<sup>th</sup> - International CFIDS Awareness Day 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**  
CFIDS message points  
Facts and figures about the Government's response to CFIDS  
Sample advocacy letter  
Sample proclamation
- **Media Information**  
Message points for talking about CFIDS  
Additional media "tips"  
Suggestions for public awareness activities  
Sample media letter
- **Letter Writing Campaign Enclosure**  
CFIDS fact sheet

The CFIDS Association of America  
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Web site: <http://www.cfids.org>

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

# GUIDELINES FOR MAY 12<sup>TH</sup>, INTERNATIONAL CFIDS 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 CFIDS Fact Sheet, which explains what CFIDS/CFS is, who gets it and how it is treated.
  - 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 CFIDS Fact Sheet in an addressed envelope, seal it, stamp it and then mail all the letters at once.
- Work to get a CFIDS Awareness Day Proclamation issued (see enclosed information).
  - Start this process early! At least 30 days are required to complete the document.

### 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 CFIDS research. Call your Senators or Representative and ask to speak to the Health Legislative Aide (each Congressperson has local offices in your state which may save you a long-distance phone call to their Washington, DC office). To find the phone numbers, look in 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 CFIDS and Awareness Day 2004.
  - Mail your letters or call the reporters early. Program directors often plan ahead and since May is a TV and radio ratings month, they are busy preparing feature stories now for broadcast in May.
- Once you have a reporter interested in CFIDS, call Marcia Harmon, the Association's Director of Publications at 704-364-0016, ext. 117 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 CFIDS *really* is.**

- Provide them with a free CFIDS Information Packet. To request a packet, call 800-442-3437 and leave their name and mailing address. For more immediate service, you may call the Association's Resource Line 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 on what information should be included 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 [www.cfids.org](http://www.cfids.org). Please remember, this display does not need to be "manned" by someone from your group.
- If members of your support group can manage some time at the mall, you may wish to set up a display there.
- 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.

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

- Give a health care provider a free Medical Information Packet from The CFIDS Association of America by calling 800-442-3437 and leaving his or her name and address. For more immediate service, you may call the Association's Resource Line.
- CFIDS Association members can also nominate two of their health care practitioners to receive a complimentary subscription to *The CFS Research Review*, the Association's medical newsletter. The *Review* provides up-to-date information on research, diagnosis and treatment of CFIDS. For complimentary practitioner subscriptions, call the Association's Resource Line.

### **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 CFIDS on May 12! Send your plans (and pictures) to The CFIDS Association of America, Attn: CFIDS Awareness Day, PO Box 220398, Charlotte, NC 28222-0398.

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

# PROCLAIM MAY 12<sup>TH</sup> INTERNATIONAL CFIDS AWARENESS DAY

## Request a Proclamation!

A proclamation will take approximately 30 days to be processed and approved, so be sure to allow sufficient time to plan this project. You may hear a proclamation referred to as a citation, a resolution, a declaration or even a congratulations. But they can all deliver your message.

### How Do We Do It?

- Meet with your support group members and discuss the possibility of requesting a proclamation sponsoring May 12<sup>th</sup> as International CFIDS Awareness Day from one or more of your elected officials (some groups request that the entire month be observed).
- Consider asking one or more of the following individuals to sponsor the proclamation:
  - Your federal Representative      Your state Representative
  - Your federal Senators            Your state Senator
  - Your Governor                      Your Mayor
- Discuss and assemble proposed language that you would like included in the proclamation (see suggestion on the following page). Please understand that the language you propose is just that—a proposal. The office may not be able to use exactly what you suggest, and some things may get reworded or changed.
- Make an appointment to meet with your elected official or an assistant in the local office.
  - Introduce yourself as a constituent of [your elected official]. Tell them you are a member of [the name of your support group, if applicable], and The CFIDS Association of America, if applicable, and that May 12th is International CFIDS Awareness Day.
  - Explain that adults and children in other states will be having proclamations sponsored that acknowledge this day and that your group would like the support of [your elected official] so that your state can participate in this international public awareness campaign.
  - Designate two or three persons to attend the appointment. Because of the size of most of the offices, it's best to limit the number of people who attend. At the same time, make sure you have one or two back-ups, in case someone is too ill to participate on the day of the appointment.
- Attend the appointment.
  - Introduce yourself and those with you and explain that you are there to request his/her support of a proclamation.
  - Submit your proposed language for the proclamation.
  - Address any questions and provide the office with additional educational material about CFIDS.
  - Keep your visit brief and thank the person you met with for his/her time and consideration of your request.

## ***Follow Up***

- Write a note thanking your elected official and/or the aide/assistant for meeting with you.
- Your elected official's office will inform you of the preparation of the proclamation.
- Attend the presentation. Again, only a small number of people should attend the presentation of the proclamation which probably will occur at the office of your elected official.
- Request permission to have pictures taken with your elected official as you are presented with the proclamation.
- Following the presentation, you may want to consider holding a public meeting to announce the proclamation, which will be an official document with the seal of the office of your elected official. One group leader suggested that the announcement be made at the local library or other public area and that the local media be invited to attend the event.
- Don't be discouraged if the first official you meet with declines to issue the proclamation. Repeat the process with another potential sponsor.

## ***What should we say?***

The included sample proclamation is a variation of a citation presented by the Commonwealth of Pennsylvania House of Representatives to the Lehigh Valley CFS Support Group. You may rework the text so that it addresses the appropriate office and fits your goals. (See sample on the following page.)

## ***Follow Up—Again!***

- Write a note of thanks to each elected official who sponsored a proclamation in support of May 12<sup>th</sup> as International CFIDS Awareness Day.

## **SAMPLE PROCLAMATION**

*Whereas, The Chronic Fatigue Syndrome Association of the Lehigh Valley joins The CFIDS Association of America in observing May 12<sup>th</sup> as Chronic Fatigue and Immune Dysfunction Syndrome Awareness Day; and*

*Whereas, Chronic fatigue and immune dysfunction syndrome (CFIDS), also known as chronic fatigue syndrome (CFS), is a complex illness which affects many different body systems and is characterized by neurological, rheumatological and immunological problems, incapacitating fatigue and numerous other symptoms that last for many months or years and can be severely debilitating; and*

*Whereas, Conservative estimates suggest that close to one million American adults and children have CFIDS; and*

*Whereas, It is imperative that education and training of health professionals regarding CFIDS be expanded and that there be greater public awareness of this serious health problem. While there has been increased activity at the state, local and national levels, more must be done to support patients and their families; and*

*Whereas, Although research efforts at the Centers for Disease Control, the National Institutes of Health and other private research institutions have strengthened, the CFS Association of the Lehigh Valley recognizes that much more must be done to encourage further research so that the mission we share with The CFIDS Association of America, "to conquer CFIDS and related disorders...", can be achieved.*

*Now therefore, the House of Representatives of the Commonwealth of Pennsylvania hereby commends the designation of May 12<sup>th</sup> as CFIDS Awareness Day and applauds the efforts of those battling the illness;*

*And directs that a copy of this citation, sponsored by [your elected official\*] be prepared for the CFS Association of the Lehigh Valley.*

*\*State or federal House of Representatives: the Honorable [full name]*

*\*State or federal Senate: Senator [full name]*

*\*Governor: the Honorable [full name]*

*\*Mayor: the Honorable Mayor [full name]*



# ADVOCACY INFORMATION

May 12<sup>th</sup> is  
International CFIDS/ME Awareness Day:  
Tell Congress That You Are Concerned 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 and immune dysfunction syndrome (CFIDS). Help continue this tradition of awareness building by asking your Members of Congress to support increased and improved CFIDS research.

Here are some simple ways you can get involved in advocacy for CFIDS 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 Internet (visit Web sites such as [www.congress.org](http://www.congress.org)).
- **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 people 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 CFIDS Congressional Advocacy Message Points document and the Facts and Figures about the Government's Response to CFIDS 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 <http://www.cfids.org/advocacy/cfids-activists-smpl-ltrs.asp>, rather than re-typing it.

You may find it more effective to send your message to Congress by fax, e-mail or telephone. 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 format:

**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 [cfids@cfids.org](mailto:cfids@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.

If you would like more specific information or help in deciding how to approach your congressional representatives or key Members of Congress, please contact Marcia Harmon, the Association's Director of Publications, by phone at 704-364-0016 or by e-mail at [mlharmon@cfids.org](mailto:mlharmon@cfids.org).

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

## 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 L/HHS Appropriations Subcommittee:

#### Republicans:

Ralph Regula, Ohio - Chairman  
Ernest J. Istook, Jr., Oklahoma  
Roger F. Wicker, Mississippi  
Anne Northup, Kentucky  
Randy "Duke" Cunningham, California  
Kay Granger, Texas  
John E. Peterson, Pennsylvania  
Don Sherwood, Pennsylvania  
Dave Weldon, Florida  
Michael K. Simpson, Idaho

#### Democrats:

David R. Obey, Wisconsin - Ranking Minority Member  
Steny H. Hoyer, Maryland  
Nita M. Lowey, New York  
Rosa DeLauro, Connecticut  
Jesse L. Jackson, Jr., Illinois  
Patrick J. Kennedy, Rhode Island  
Lucille Roybal-Allard, California

### Senate L/HHS Appropriations Subcommittee:

#### Republicans:

Arlen Specter, Pennsylvania - Chairman  
Thad Cochran, Mississippi  
Judd Gregg, New Hampshire  
Larry Craig, Idaho  
Kay Bailey Hutchison, Texas  
Ted Stevens, Alaska  
Mike DeWine, Ohio  
Richard Shelby, Alabama

#### Democrats:

Tom Harkin, Iowa - Ranking Minority Member  
Ernest Hollings, South Carolina  
Daniel Inouye, Hawaii  
Harry Reid, Nevada  
Herb Kohl, Wisconsin  
Patty Murray, Washington  
Mary Landrieu, Louisiana

### House Energy & Commerce Committee - Subcommittee on Health:

#### Republicans:

Michael Bilirakis, Florida - Chairman  
Joe Barton, Texas

Fred Upton, Michigan  
James C. Greenwood, Pennsylvania  
Nathan Deal, Georgia  
Richard Burr, North Carolina  
Ed Whitfield, Kentucky  
Charlie Norwood, Georgia – Vice Chairman  
Barbara Cubin, Wyoming  
Heather Wilson, New Mexico  
John B. Shadegg, Arizona  
Charles W. “Chip” Pickering, Mississippi  
Steve Buyer, Indiana  
Joseph R. Pitts, Pennsylvania  
Michael Ferguson, New Jersey  
Michael Rogers, Mississippi  
W.J. “Billy” Tauzin, Louisiana (ex officio)

**Democrats:**

Sherrod Brown, Ohio - Ranking Minority Member  
Henry A. Waxman, California  
Edolphus Towns, New York  
Frank Pallone, Jr., New Jersey  
Anna G. Eshoo, California  
Bart Stupak, Michigan  
Eliot L. Engel, New York  
Gene Green, Texas  
Ted Strickland, Ohio  
Lois Capps, California  
Bart Gordon, Tennessee  
Diana DeGette, Colorado  
Christopher John, Louisiana  
John D. Dingell, Michigan(ex officio)

**Senate Health, Education, Labor And Pensions (HELP) Committee:**

**Republicans:**

Judd Gregg, New Hampshire - Chairman  
William Frist, Tennessee  
Mike Enzi, Wyoming  
Lamar Alexander, Tennessee  
Christopher Bond, Missouri  
Mike DeWine, Ohio  
Pat Roberts, Kansas  
Jeff Sessions, Alabama  
John Ensign, Nevada  
Lindsey Graham, South Carolina  
John Warner, Virginia

**Democrats:**

Edward Kennedy, Massachusetts - Ranking Minority Member  
Christopher Dodd, Connecticut  
Tom Harkin, Iowa  
Barbara Mikulski, Maryland  
Jeff Bingaman, New Mexico  
Patty Murray, Washington  
Jack Reed, Rhode Island  
John Edwards, North Carolina  
Hillary Rodham -Clinton, New York

As one of your voting constituents, I ask that you support increased research on chronic fatigue and immune dysfunction syndrome (CFIDS), also known as chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME). More than 800,000 American men, women and children of all races and socioeconomic classes have CFIDS. CFIDS is a terribly debilitating and serious illness, with symptoms including incapacitating fatigue (experienced as profound exhaustion and extremely poor stamina), muscle and joint pain, information processing and concentration problems and numerous other symptoms. People with CFIDS function at a substantially lower level of activity than they were capable of before becoming ill.

Although there have been many advances in the understanding of CFIDS, it remains a complex and difficult disease to diagnose and treat. Improved understanding is severely hampered by inadequate funding for the critical research needed to better define its impact and identify more effective treatments to ultimately find the cause, effective treatment and a cure. In a 2001 survey fielded to more than 8,100 medical professionals from a variety of disciplines, 77 percent felt that the amount of professional education about CFIDS is not adequate and 87 percent indicated a need for more funding for CFIDS research.

Therefore, I urge you to support legislation, such as that advocated by The CFIDS Association of America, which will increase the amount and the quality of research on CFIDS by our national public health agencies. Please help us increase awareness of CFIDS by recognizing May 12<sup>th</sup> as International CFIDS Awareness Day. Thank you for your consideration of these important matters.

Sincerely,

# FACTS AND FIGURES ABOUT THE GOVERNMENT'S RESPONSE TO CFIDS

Following is some background information about the government's CFIDS-related activities. You do *not* need to memorize these items; a general familiarity with them will better prepare you for meeting with or writing to 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 CDC has recently developed a process for scientifically "optimizing" the case definition to make its use more consistent and to address differences in research and clinical settings.
- CDC and the National Institutes of Health (NIH) have each funded research on the prevalence of CFIDS. Current estimates indicate at least 800,000 Americans have strictly defined CFIDS. Estimates of "CFIDS-like" illness are much, much higher.
- Between 1990 and 2001, NIH and CDC invested about \$113 million in CFIDS research (\$48 million at CDC and \$64 million at NIH).

## Stagnation in Government Funding

- NIH's CFIDS funds have changed little since the mid-1990s.
  - CFIDS funding nearly tripled from 1990-95, but fell by 16 percent over the following five years.
  - Beginning in FY99, NIH received annual funding increases from Congress toward doubling its overall budget in five years. The doubling will be completed in FY03. Congress' intent that these large increases would benefit all research areas has failed CFIDS research.
- CDC reported to Congress that it had spent \$5.8 million on CFIDS research annually from 1995-98, but actually it was spending only 48-72 percent of that total each year. Based on documents obtained through the Freedom of Information Act, we believe that reports of prior years' funding are also inaccurate.

## Misappropriation of Funds

- In May 1999, the Department of Health and Human Services (DHHS) Inspector General reported that, between 1995 and 1998, CDC had intentionally misrepresented to Congress the amount of money it had spent on CFIDS and that more than half the funds — \$12.9 million of \$22.7 million — were actually spent to research other, unrelated illnesses.

- After great pressure from CFIDS advocates and Congress, CDC agreed to restore the full \$12.9 million diverted from CFIDS research over a four-year period (2000-2003). CDC initially offered to restore only \$8.8 million to CFIDS.
- In June 2000, the General Accounting Office released a report noting a series of deficiencies in CFIDS programs at the NIH, CDC and DHHS.
- CDC has greatly expanded its internal research programs and has provided support to outside CFIDS researchers using the restored funds. It has also supported education efforts directed at primary care providers. The Association remains vigilant over the use of all federal funds.

### **Progress**

- In December 2001, the NIH released its first CFIDS Program Announcement (PA) since 1996. This PA serves as a formal announcement to researchers that NIH is interested in funding CFIDS research. The PA was co-sponsored by 7 NIH institutes, one center and three offices. However, since NIH didn't set aside any monies to fund CFIDS research submitted under the new PA, there is no guarantee that CFIDS funding will increase.
- The NIH Office of the Director is now responsible for managing and coordinating CFIDS programs at NIH, creating the opportunity for a stronger multi-disciplinary approach to CFIDS research.
- The Chronic Fatigue Syndrome Advisory Committee (CFSAC) meets quarterly to discuss research, education, disability and other issues that agencies of the U.S. Department of Health and Human Services (DHHS) can address. Eleven members of the public, 7 researchers and 4 broadly defined others, comprise the committee. Representatives from the National Institutes of Health, Centers for Disease Control, Food and Drug Administration, Health Resources and Services Administration and the Social Security Administration provide updates and technical information to the committee. Members of the public are invited to attend and/or present testimony at the quarterly meetings, usually held in Washington, D.C.
- In April 1999, the Social Security Administration (SSA) responded to grave disparities in handling of CFS claims by releasing a ruling on the proper adjudication of CFS claims. This ruling (SSR 99-2p) has reportedly improved CFS claims handling and tracking across the U.S., according to CFIDS patients, disability attorneys and SSA officials.
- NIH and CDC co-sponsored The CFIDS Association of America 2000-2001 research symposia series. The agencies' willingness to work closely with a patient advocacy organization signals a new openness and acceptance toward citizens' concerns.

# CFIDS CONGRESSIONAL ADVOCACY MESSAGE POINTS

Below are message points that you can use when writing or talking to your congressional representatives about CFIDS. Message points help make sure the information and requests that the Association is providing Congress are consistent and credible. You do not need to mention every point, but they can serve as an outline of what to cover.

## INTRODUCTION TO CFIDS

**The CFIDS Association is asking that every member of Congress make CFIDS a priority, given the magnitude of the illness and its impact on the communities they represent.**

- Chronic fatigue and immune dysfunction syndrome (CFIDS), also called chronic fatigue syndrome (CFS), is a serious medical condition that is difficult to diagnose and treat. Symptoms of CFIDS include incapacitating fatigue, impaired memory or concentration, tender lymph nodes, muscle and joint pain, headaches, unrefreshing sleep and fatigue lasting more than 24 hours following exertion.
- A study published in the *Archives of Internal Medicine* estimates that approximately 422 out of 100,000 people—or more than 800,000 people in the U.S.—have CFIDS. It is three times more common in women than it is in men, and it disproportionately affects blacks and Hispanics and people of lower socioeconomic status.
- The same study found that 90 percent of all patients have not been diagnosed and are not receiving proper medical care for their illness.
- CFIDS strikes people during their most productive years. Although few long-term studies of the illness have been done, CDC estimates the recovery rate to be less than 12 percent.
- The CFIDS Association receives inquiries from people with CFIDS in every state and many countries around the world. In 2002, the Association recorded nearly 600,000 visits to its Web site and responded to more than 8000 personal requests for information.
- The CFIDS Association recognizes the special role that members of the House and Senate Appropriations Committees can play in helping people with CFIDS and is actively working to engage those members of Congress.
- Please support our mission to conquer CFIDS by sending a letter supporting the following requests to the chairman and ranking minority members of the Labor/HHS Appropriations Subcommittee.

## **CFIDS ASSOCIATION CONGRESSIONAL REQUESTS**

**The CFIDS Association asks Congress to direct the Centers for Disease Control and Prevention to provide sufficient funding to: maintain the high caliber of its CFIDS research program; educate health care providers about the detection, diagnosis and management of CFS; and better inform the public about the severity and magnitude of CFIDS.**

- With \$12.9 million restored to its CFIDS program as a result of the 1995-98 diversion of funds (documented by the inspector general) the CDC is branching into new and important areas of CFIDS research and medical education.
- The President's proposed cuts to the CDC budget, combined with an emphasis on bioterrorism and security threats, may stall the agency's important CFIDS work.

**The CFIDS Association requests that Congress direct NIH to target an additional \$10 million in grants to focus on promising areas of CFIDS research, such as efforts to understand the cause and progression of CFIDS, identify diagnostic markers and focus on pediatric CFIDS, by funding both multidisciplinary CFIDS research and investigator-initiated studies.**

- NIH funding for CFIDS research has declined since 1995, despite the fact that the Congress has doubled its budget over the past five years. At the same time, estimates of CFIDS prevalence have risen from 10,000 to 800,000 affected American men, women and youth.
- Scientists are attracted to areas in which they believe they can obtain funding for their work; designated NIH funds for CFIDS research would draw experienced, top-quality scientists to this field.

**The CFIDS Association requests that Congress direct HRSA to provide demonstration grants to develop model clinical centers with the goal of optimizing and delivering effective, multidisciplinary clinical care to people with CFIDS.**

- CFIDS patients' most crucial need is for effective, compassionate medical care. HRSA has supported demonstration grants to find new, more effective ways to deliver health care for emerging illnesses, although it has not yet done so for CFIDS.

**The CFIDS Association requests that Congress direct the Secretary for Health to provide leadership across the DHHS agencies to strengthen and ensure coordination of federal CFIDS programs.**

- The federal DHHS CFS Advisory Committee is an essential mechanism to ensure that federal research and education programs are adequate and effective. This committee also

enables patient advocates to participate in policy decisions and to hold agency representatives accountable for the use of federal funds.

**The CFIDS Association asks Congress to instruct the Department of Education to maintain its recognition of CFIDS as an unmet area of research for the National Institute on Disability and Rehabilitation Research.**

Little research has been done on the functional limitations resulting from CFIDS and ways in which CFIDS patients could benefit from rehabilitation strategies and technologies to reduce disability and improve quality of life.



# MEDIA INFORMATION

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

## HOW TO GET INVOLVED IN CFIDS MEDIA OUTREACH

Approaching the media about covering CFIDS is an essential part of May 12<sup>th</sup> CFIDS Awareness Day. Congressmen and senators 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 CFIDS is an issue worthy of their attention.

The CFIDS Association understands that people with CFIDS (PWCs) 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 do not 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 CFIDS Fact Sheet. 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, 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 CFIDS. 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 will be in getting your message across.

If you find that you are 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 that you have read in a publication. Look for articles that can have special meaning for CFIDS 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 PWCs 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 CFIDS 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 get a visual element to the story via photographs or video footage.

You do not need to tackle all of these activities simultaneously. Do only what your health and energy level allows. If all of these activities are above your energy level, or you find that 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 are building on the efforts of other PWCs around the country to increase public awareness of CFIDS.

If you would like more specific information or help in deciding how to approach your local media, we encourage you to contact Marcia Harmon, the Association's Director of Publications, by phone at 704-364-0016, ext. 115 or by e-mail at [mlharmon@cfids.org](mailto:mlharmon@cfids.org).

## SUGGESTED MESSAGE POINTS FOR TALKING ABOUT CFIDS

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

- **CFIDS is more than just fatigue.** Chronic fatigue and immune dysfunction syndrome (CFIDS) is a serious, debilitating medical condition. The name of the illness does not adequately reflect its complexity. In addition to severe fatigue, individuals with CFIDS experience cognitive problems, pain in the muscles and joints, tender lymph nodes, headaches and many other symptoms.
- **CFIDS is a real medical condition.** There is no known cause or cure for CFIDS; however, scientists have identified numerous biological abnormalities in CFIDS patients. One leading theory is that the illness is rooted in the immune system, endocrine system and central nervous system. When any of these systems is activated, the others are affected.
- **CFIDS is underdiagnosed.** Fewer than 10 percent of people with CFIDS have been diagnosed by a medical practitioner. More than 90 percent remain ill with little or no medical treatment. CFIDS is often misdiagnosed because it can mimic many other disorders, including multiple sclerosis, Lyme disease and lupus.
- **CFIDS 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.
- **CFIDS is not psychological in origin.** Medical studies have proven CFIDS is not "all in the head," laziness or a mental disorder that can be cured with psychiatric treatment. Some patients are also clinically depressed, but that is understandable, given the debilitating nature of the symptoms.
- **CFIDS affects everyone.** CFIDS used to be thought of as the "yuppie flu," affecting white, middle-class professionals. Recent studies have changed that image, showing that CFIDS strikes men, women and children of all age, ethnic and socioeconomic groups.
- **CFIDS is variable.** As with autoimmune disorders, CFIDS affects each individual differently. Patients range from being mildly affected to being completely homebound. Some people "recover" (fewer than 12%, according to research), some cycle between periods of relatively good health and severe illness, and some gradually worsen over time. Others improve but never fully recover.
- **CFIDS can be severe.** According to the CFIDS Association's recent survey of more than 8,000 medical professionals, physicians believe CFIDS is as disabling or more

disabling than other more well-known chronic illnesses, such as lupus or multiple sclerosis. People with CFIDS can be so ill that they cannot complete the daily tasks of living, such as eating, showering or sitting up in bed. They may require a wheelchair or be completely bedbound.

- **CFIDS is a serious public health problem.** The majority of cases in the United States are found in women between the ages of 40-49. CFIDS is three times more common than HIV infection in women and 25 times more common than AIDS among women, yet receives far less media attention and research funding.
- **People with CFIDS need your help.** There is still much to be learned about CFIDS. Legislators, the research community and the general public need to call for increased research and education. We need to work together to conquer this complex medical mystery and help the millions around the world who live with the nightmare of CFIDS every day to reclaim their lives.

### OTHER THINGS TO KEEP IN MIND

- **Use the name chronic fatigue and immune dysfunction syndrome (CFIDS)** when talking about the illness to the general public and consumer-oriented media. The illness is also called chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME), and switching between names can be very confusing for your audience. The CFIDS Association prefers to call the illness CFIDS for the sake of consistency and clarity in interviews.
- **CFIDS is not chronic fatigue.** Chronic fatigue can be caused by many different medical conditions, including cancer, anemia and diabetes. CFIDS is a unique illness with a specific set of symptoms. An individual has to have been severely fatigued for at least six months to be diagnosed with CFIDS.
- **The illness needs to be taken seriously.** CFIDS is often met with skepticism and the statement “I’m tired, too, so I must have it.” Calmly responding that they would not wish to have CFIDS since it is so debilitating is a good response. Also, audiences sometimes interpret “there is no known cause or cure” as proof that the illness is not 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 CFIDS 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 CFIDS, especially one about medical treatment or research, you can direct the individual to the CFIDS Association’s Director of Publications, Marcia Harmon, at 704-364-0016, ext. 117 or [mlharmon@cfids.org](mailto:mlharmon@cfids.org). The Association will be able to answer or put the person in touch with an appropriate resource.

## SUGGESTIONS FOR PUBLIC AWARENESS ACTIVITIES

*The guidelines at the front of this packet list ways that you can alert the media, health care providers and the general public about CFIDS. Here are some additional ideas for increasing awareness, including a few suggestions that involve very little time and energy, for those who are not physically able to tackle large projects. If you would like more specific information or assistance, please call Marcia Harmon, Director of Publications, at 704-364-0016, ext. 117 or e-mail to mlharmon@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 CFIDS Fact Sheet 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 web site, 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.
- **Give presentations on CFIDS** to church, women's, civic, school, and youth groups. (*Hint: you could ask a local health care practitioner, friend or family member knowledgeable about CFIDS 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 CFIDS before or on May 12.
- **Explore opportunities to partner with other local health groups** to spread the word about CFIDS 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 CFIDS Fact Sheet included in this packet.
- **Create a simple public service announcement (PSA)** and send it to local publications and radio stations. (*Hint: you may be able to find a local graphic designer willing to desktop publish your text for free. The CFIDS Association can provide you with sample PSAs.*)
- **Leave information at local businesses.** Some companies have bulletin boards or allow health-related information to be left in their lunch rooms. You could ask friends and family to see if their workplaces would allow them to leave information about CFIDS for employees.

## ADDITIONAL TIPS FOR DEALING WITH THE MEDIA

*This list provides some additional guidance on working with reporters to increase awareness of CFIDS and related disorders for CFIDS Awareness Day*

- **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 do not know the answer to a question, such as an inquiry about a specific piece of CFIDS-related research, say so. Offer to find out for the reporter or refer him/her to Marcia Harmon, Director of Publications at 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 CFIDS-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.
- **Do your media homework.** Reporters are always wary of news that they have heard before or don’t feel is applicable to their audience. If you are going to call reporters to encourage them to run a story on CFIDS, check what kind of health care coverage that media outlet has run recently. For example, approaching a reporter saying something like, “I know your paper has run a story on multiple sclerosis in the last month. CFIDS is another immune disorder that is even less well known, but has a real impact on this community...” may net you better results.
- **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 do not want to see in print or on the air. If you catch yourself doing just that, explain to the reporter why that quote should not be used—for example, it may be misleading or confusing to his/her audience.

Dear

May 12, 2004 will be the twelfth annual international chronic fatigue and immune dysfunction syndrome (CFIDS) Awareness Day. To increase the general public's understanding of CFIDS, also known as chronic fatigue syndrome (CFS), persons with CFIDS around the world will be conducting CFIDS awareness activities on May 12<sup>th</sup>. Please help us educate health care consumers about this debilitating condition by reporting about CFIDS on or around May 12<sup>th</sup>.

Because of the name of this disease, many people mistake CFIDS simply for fatigue or chronic fatigue. Nearly everyone has been fatigued at some point in time, but comparing general tiredness to chronic fatigue syndrome is like comparing a wind gust to a hurricane. The symptoms of CFIDS include incapacitating fatigue (profound exhaustion and poor stamina), muscle and joint pain, information processing and concentration problems and numerous other symptoms. While no one has yet fully defined what causes CFIDS, scientists have learned that it is a complex disorder that affects many of the body's systems, including the brain and immune system.

CFIDS is estimated to affect as many as 800,000 Americans, but the medical community lacks the knowledge and tools to diagnose it effectively. In a 2001 survey fielded to over 8,100 medical professionals and researchers from a variety of disciplines, 77 percent of respondents feel that the amount of professional education about CFIDS is not adequate and that more is needed. Eighty-seven percent indicated that more funding for CFIDS research is needed. I believe that people in our community would be interested to learn about CFIDS—both to help them understand the difference between ordinary fatigue and CFIDS and to help those who suffer from it but have yet to be diagnosed.

The CFIDS Association of America has a Resource Line (704-365-2343) and a Web site ([www.cfids.org](http://www.cfids.org)) that you can include to give readers a way to request free information about CFIDS. You can also call the Association's media contact line at 704-364-0466 for more information, to request a media kit or to arrange interviews with other CFIDS patients in our community.

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 to helping you create a very successful feature about CFIDS 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.

# Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS)

## *Fact Sheet*

Chronic fatigue and immune dysfunction syndrome (CFIDS) is also called chronic fatigue syndrome (CFS). It is recognized by the National Institutes of Health, U.S. Centers for Disease Control and Prevention, Food and Drug Administration and Social Security Administration as a serious, disabling illness.

CFIDS is characterized by unrelenting exhaustion, muscle and joint pain, cognitive disorders and other symptoms. Many people with CFIDS are denied disability benefits because doctors and employers wrongly believe they are lazy or have a mental illness rather than a serious physical condition.

Research on CFIDS is being conducted on many fronts, but the cause of the disease remains a mystery.

### **SYMPTOMS**

- According to the CDC, CFIDS is characterized by fatigue that is medically unexplained; of new onset; lasts at least six months; is not the result of ongoing exertion; is not substantially relieved by rest; and causes a substantial reduction in activity levels.
- CFIDS fatigue must be accompanied by four or more of the following symptoms: impaired memory/concentration; sore throat; tender neck or armpit lymph nodes; muscle pain; headaches of a new type, pattern or severity; unrefreshing sleep; relapse of symptoms after exercise; and pain in multiple joints.
- Symptoms can be severe. A survey of more than 8,000 medical professionals conducted by The CFIDS Association showed most physicians believe CFIDS is as or more disabling than lupus, rheumatoid arthritis and similar chronic conditions.

### **DIAGNOSIS**

- There is no proven diagnostic test that identifies CFIDS in all cases.
- CFIDS is often difficult to recognize because it can resemble many other illnesses, including mononucleosis, multiple sclerosis, Lyme disease and fibromyalgia.
- To make a diagnosis, physicians must rule out other possible causes of symptoms, such as other medical disorders and medications known to cause fatigue.
- Fewer than 10 percent of CFIDS patients have been diagnosed and are receiving proper medical care for their illness.

### **PREVALENCE**

- A study conducted by DePaul University estimates that as many as 800,000 people nationwide suffer from CFIDS.
- CFIDS has been shown to affect people of all races, ages and socioeconomic groups.
- Research has confirmed that CFIDS is three times as common in women as men. It is more common than multiple sclerosis, lupus, HIV infection and lung cancer in women.
- Although few studies of CFIDS in children and adolescents have been published, it has been documented that children can get CFIDS, although less frequently than adults.

## RECOVERY

- CFIDS affects each individual differently. Some people with CFIDS remain homebound and others get better to the point that they can resume work and other activities, even though they continue to experience symptoms.
- “Recovery” rates for CFIDS are unclear. According to one of the few published studies, the probability of significant improvement was about 30 percent during the first five years of illness and 48 percent during the first 10 years. However, even “recovered” patients stated that they still had some CFIDS symptoms, and one-third had relapsed six months later.

## TREATMENT

- Since there is no known cure for CFIDS, treatment is aimed primarily at symptom relief. No single therapy exists that helps all patients with CFIDS.
- Lifestyle changes, including increased rest, reduced stress, dietary restrictions, gentle stretching and nutritional supplementation, are frequently recommended.

## CAUSE

- Despite an intensive, nearly 20-year search, the cause of CFIDS remains unknown. Many different infectious agents, toxins and psychological causes have been considered and rejected, but the search continues.
- Much of the ongoing research into a cause has centered on the role the immune, endocrine and nervous systems may play in CFIDS.
- Genetic and environmental factors may play a role in developing and/or prolonging the illness, although more research is needed.

## NAME

- CFIDS is also known as chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME). It is widely acknowledged that the name chronic fatigue syndrome is inadequate and demeaning, given the breadth and seriousness of the symptoms. Advocates and federal officials are working together to find a new name.

## GOVERNMENT RESPONSE

- CFIDS is a leading public health problem, yet federal funding for research on the illness has declined since 1995. The CFIDS Association continues to press Congress and federal health agencies to allocate more resources to the investigation of CFIDS.
- In 1999, the Social Security Administration issued guidelines for determining disability benefits for persons with CFIDS. This recognition of CFIDS as a disabling condition is a major step forward for patients who can no longer work as a result of the illness.

## ABOUT THE CFIDS ASSOCIATION OF AMERICA

- The CFIDS Association of America is the leading organization dedicated to conquering CFIDS and related disorders. The Association has invested more than \$13 million in CFIDS research, education and public policy efforts.
- The Association publishes *The CFIDS Chronicle*, the world’s most authoritative source of information about CFIDS, and *The CFS Research Review*, a source of information on diagnosis, treatment and research for medical professionals.

To learn more about CFIDS, call The CFIDS Association of America’s toll-free number 24 hours a day (800-442-3437) or visit [www.cfids.org](http://www.cfids.org).

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