

# 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
- **Lobby Day Information**  
Please join us this year on September 17-18!!

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

Resource Line: 704-365-2343  
Fax: 704-365-9755  
Email: [cfids@cfids.org](mailto:cfids@cfids.org)  
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 websites 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 2005.
  - 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 Communications, at 704-364-0466, 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 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<sup>th</sup> 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 website 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<sup>th</sup> 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 call the Association's Resource Line at 704-365-2343.
- 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<sup>th</sup>! Send your plans (and pictures) to The CFIDS Association of America, Attn: CFIDS Awareness Day, PO Box 220398, Charlotte, NC 28222-0398. We will be doing a CFIDS 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!***

# 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 12<sup>th</sup> 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 websites such as *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 Communications, by phone at 704-364-0466 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.**

# **INFORMATION ABOUT THE CFIDS COMMUNITY AND THE CFIDS ASSOCIATION OF AMERICA Lobby Day 2005**

**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.**

- The CFIDS Association receives inquiries from persons with CFIDS in every state and many countries around the world. In 2004, the Association recorded nearly 800,000 visits to its Web site and responded to over 6,500 personal requests for information.
- A study published in the July 14, 2003 issue of *Archives of Internal Medicine* estimates that 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 persons of lower socioeconomic status.
- The same study found that 86 percent of all patients have not been diagnosed and are not receiving proper medical care for their illness.
- CFIDS strikes people during the prime of their most productive years. Although few long-term studies of the illness have been done, CDC estimates the rate of full recovery to be less than 12 percent.
- A recent CDC study estimates lost productivity related to CFIDS is \$9.1 billion each year, roughly the equivalent of Wal-Mart's annual profits.
- The CFIDS Association recognizes the special role that members of the House and Senate Appropriations Committees can play in advancing progress for persons with CFIDS and is actively working to develop support from those members of Congress.

**Since the CFIDS community began working with Congress in 1992 to improve the nation's CFIDS programs, there have been numerous important victories for CFIDS patients.**

- The Social Security Administration has recognized CFIDS as a disabling condition with Ruling 99-2p.
- The Inspector General exposed massive misspending at CDC of funds Congress directed to be spent on CFIDS, resulting in restoration of \$12.9 million to the CFIDS research program. Restoration of these funds to CFIDS research will be completed by the end of FY05 (Sept. 30, 2005).
- The CDC is now running one of the most comprehensive CFS research programs in the world including clinical studies, lab studies, collaborative efforts and analysis of the impact of CFIDS as a major public health concern.
- The Office of the NIH Director is responsible for NIH-wide coordination of CFIDS-related research, creating the opportunity for a stronger multidisciplinary approach to CFIDS research.
- The Department of Health and Human Services has chartered a federal advisory committee, the Chronic Fatigue Syndrome Advisory Committee (CFSAC), to make policy recommendations on CFS-related issues. The 11 appointees to the CFSAC meet quarterly with officials from the NIH, CDC, SSA, Food and Drug Administration and the Health Resources and Services Administration to review federally-sponsored research and education programs.

- The CFIDS Association of America has invested more than \$4 million in CFIDS research since 1987, much of it seeding new research projects that go on to receive NIH or CDC support. Only the federal government has funded more CFIDS research than the Association.
- Over the past 13 years, hundreds of CFIDS advocates have participated in the Association's annual Lobby Day events at their own expense in order to raise awareness about CFIDS among Members of Congress and their staff.

# INFORMATION ABOUT THE GOVERNMENT'S RESPONSE TO CFIDS Lobby Day 2005

Following is some background information about the government's CFIDS-related activities. You do *not* need to memorize these facts; a general familiarity with them will better 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 last year 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 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.
- CDC has studied the direct economic impact of CFIDS. Each year CFIDS costs our country \$9.1 billion in lost productivity. Adding medical costs and disability benefits push this number much higher.
- Over 14 years, between 1990 and 2004, NIH and CDC invested about \$160 million in CFIDS research (\$80 million at CDC and \$80 million at NIH).

## Stagnation in Government Response

- NIH's CFIDS funds are at their lowest point since the mid-1990s.
  - The current level of actual funding is less than \$4 million for 2004. NIH is reporting a higher figure than this, but the CFIDS Association carefully analyzed their information and found that the figures are inflated by 20% through the inclusion of studies that have nothing to do with CFS. A report documenting this is available from the CFIDS Association. It has been presented to the government's CFS Advisory Committee and several Congressional appropriators.
  - Congressional efforts to double NIH's budget have failed to expand funding for CFS research and research on several other diseases.
  - In June 2003, Dr. Vivian Pinn, director of the Office of Research on Women's Health, announced at a public meeting that NIH would issue a Request for Applications (RFA) for CFS with dedicated funds to support meritorious proposals. Nearly two years later we still await the release of this RFA.
- The federal CFS Advisory Committee (CFSAC) has been meeting quarterly since September 2003. The CFSAC issued a set of recommendations on August 23, 2004 covering research and education priorities for the Department of Health and Human Services. As of the committee's most recent meeting, held April 4, 2005, the Secretary of Health has not responded to these recommendations.

## Restoration of CDC Funds

- 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 CFIDS 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, CFIDS advocates and Congress resulted in CDC agreeing to restore the full \$12.9 million diverted from CFIDS. Initially CDC offered to restore just \$8.8 million to CFIDS research.
- CDC has greatly expanded its internal research programs and has provided support to outside CFIDS 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 CFIDS as a major public health concern. The Association remains vigilant over the use of all federal funds.

## Progress

- 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 health care providers and the public about CFS.
- In December 2004, NIH released a CFS Program Announcement (PA). This PA serves as a formal announcement to researchers that NIH is interested in funding CFIDS research. 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 responsible for managing and coordinating CFIDS programs at NIH. A Trans-NIH Working Group meets periodically to hear research presentations and discuss collaborative efforts that might benefit CFIDS.
- Last month NIH released proceedings from a conference on Neuro-Immune Mechanisms in CFS.
- In April 1999, the Social Security Administration (SSA) responded to disparities in 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 CFIDS patients, disability attorneys and SSA officials.

# TALKING POINTS FOR CAPITOL HILL MEETINGS

## Lobby Day 2005

### DISCUSSION TOPICS

1. Support for the CFS Advisory Committee's (CFSAC) recommendations to the Secretary for Health and Human Services.
2. Decline in research funding at National Institutes of Health (NIH) and the need to push NIH to issue a "Request for Applications" (RFA) for CFS.
3. Support for education and research funding at the Centers for Disease Control and Prevention (CDC)

### ***What do you know about chronic fatigue syndrome?***

Chronic fatigue syndrome, also called chronic fatigue and immune dysfunction syndrome (CFIDS), is a serious and complex illness that's poorly understood. Unfortunately, the misleading name minimizes other symptoms that also define the illness. Other symptoms include cognitive difficulties, sore throat, tender lymph nodes, widespread joint and muscle pain and headaches. Everyone gets tired now and then, but comparing normal tiredness to CFS is like comparing a wind gust to a hurricane.

Develop a brief (no more than one minute) personal story that illustrates the severity and impact of the illness on everyday life. Here are some examples of illustrations others have used:

- "I was a high school math teacher; now I can't balance my checkbook or read books to my own kids."
- "Most days I have to choose between taking a shower or having dinner at the table with my family. My husband has had to take on my share of family responsibilities in addition to being the bread-winner."
- "I wasn't well enough to attend class, my graduation ceremony or the prom and I don't know if I'll ever have the stamina and concentration to learn how to drive."

***There are a great many needs, but we have prioritized three areas of concern:***

### **NIH**

- In spite of the fact that the agency's budget doubled between 1999-2004, CFS research declined during that same period. Right now, CFS research stands at just \$4 million a year – hardly adequate for a serious, chronic condition that affects roughly 1 million Americans.
- In addition, the NIH's budget office overstated the amount of CFS research being funded by NIH by 20%, by including studies that even the lead researchers said had nothing to do with CFS.
- Every year the appropriations committees have thoughtfully encouraged NIH to expand its CFS research program and they have ignored this direction. Without specific instruction from Congress, we are concerned that CFS research funds will dwindle even further.
- **In June 2003, Dr. Vivian Pinn made a formal commitment to issue a special Request for Applications (RFA) that emphasizes multi-disciplinary studies of CFS. We enthusiastically support this. Designated NIH funds for CFS research would draw new, experienced, top quality scientists to this field. However, nearly two years later, Dr. Pinn's commitment to issue an RFA remains unfulfilled. The CFS Advisory Committee has included an RFA as one of its top priority recommendations to the Secretary for Health.**

## **CFSAC**

- The Chronic Fatigue Syndrome Advisory Committee (CFSAC) to the Department of Health and Human Services has met quarterly since September of 2003.
- **The CFSAC issued a series of 11 recommendations to the Secretary for Health on August 23, 2004. We ask for your support of full and immediate implementation of these recommendations through a letter to Secretary Leavitt.**

## **CDC**

- From 1995-1998, \$12.9 million earmarked for CFS research was diverted to other programs. Pressure from CFS advocates and Congress resulted in restoration of the full \$12.9 million to the CFS program over a five-year period (2000-2005).
- CDC is running the most comprehensive CFS program in the U.S.
- CDC is supporting education efforts directed at primary care providers and public awareness programs.
- **At the end of this fiscal year (FY05), all the payback funds will be exhausted. To continue the positive momentum in research and education, we must to maintain the funding of CFS programs by increasing the FY06 baseline to the current level of funding (\$11 million).**

## ***Supporting Information***

- According to CDC studies, at least **800,000 Americans suffer from CFS** – the actual number is likely much higher than this.
- Fewer than **20% of those are properly diagnosed**, leaving more than 80% without proper medical care for their illness.
- CFS affects people of **all races, ages and socioeconomic groups**, although women are more likely to have CFS than men and adults are at greater risk than children or adolescents.
- CDC has documented that CFS has a direct impact on the nation's economy of **\$9.1 billion a year** in lost productivity (not including medical costs).
- **The magnitude of CFS makes it a significant public health concerns that warrants greater attention and commitment from the federal government.**

## ***WHAT TO ASK FOR:***

- **Sign on to a letter to HHS Secretary Leavitt that seeks immediate implementation of 11 recommendations from the Chronic Fatigue Syndrome Advisory Committee (CFSAC).**
- **Call the Chair and Ranking Minority Leader of the Labor/HHS Appropriations Subcommittee and tell them to push NIH to issue a "Request for Applications" (RFA) for CFS.**
- **Support CFS education and research funding at the Centers for Disease Control and Prevention (CDC) by increasing the FY06 baseline to the current level of funding (\$8.9 million).**

# KEY MEMBERS OF CONGRESS

## Lobby Day 2005

Members of the House and Senate Labor, Health and Human Services, Education and Related Agencies (LHHS) Appropriations subcommittees are our top priority every year because members of these committees determine health-related funding for research, education and care. This year, the House Energy and Commerce subcommittee on Health and the Senate HELP Committee will develop important legislation titled the NIH Reauthorization Act. A primer on the process of reauthorizing NIH is included in your materials.

### House L/HHS Appropriations Subcommittee

#### Republicans

Ralph Regula, OH-16(Chairman)  
Ernest Istook, Jr., OK-5  
Roger Wicker, MS-1  
Anne Northup, KY-3 (Vice Chairman)  
Randy "Duke" Cunningham, CA-50  
Kay Granger, TX-12  
John E. Peterson, PA-5  
Don Sherwood, PA-10  
Dave Weldon, FL-15  
James Walsh, NY-25

#### Democrats

David Obey, WI-7 (Ranking)  
Steny Hoyer, MD-5  
Nita Lowey, NY-18  
Rosa DeLauro, CT-3  
Jesse Jackson, Jr., IL-2  
Patrick Kennedy, RI-1  
Lucille Roybal-Allard, CA-34

### Senate L/HHS Appropriations Subcommittee

#### Republicans

Arlen Specter, PA (Chairman)  
Thad Cochran, MS  
Judd Gregg, NH  
Kay Bailey Hutchinson, TX  
Larry Craig, ID  
Ted Stevens, AK  
Mike DeWine, OH  
Richard Shelby, AL

#### Democrats

Tom Harkin, IA (Ranking)  
Daniel Inouye, HI  
Harry Reid, NV  
Herb Kohl, WI  
Patty Murray, WA  
Mary Landrieu, LA  
Richard Durbin, IL

### House Commerce Committee - Subcommittee on Health

#### Republicans

Nathan Deal, GA-10  
Ralph Hall, TX-4  
Michael Bilirakis, FL-9  
Fred Upton, MI-6  
Paul Gillmor, OH-5  
Charlie Norwood, GA-9  
Barbara Cubin, WY-at large  
John Shimkus, IL-19  
John Shadegg, AZ-3  
Charles Pickering, MS-3  
Steve Buyer, IN-4  
Joseph Pitts, PA-16  
Mary Bono, CA-45  
Mike Ferguson, NJ-7  
Mike Rogers, MI-8  
Sue Myrick, NC-9  
Michael Burgess, TX-26  
Joe Barton, TX-6 (ex-officio)

#### Democrats

Sherrod Brown, OH-13 (Ranking)  
Henry Waxman, CA-30  
Edolphus Towns, NY-10  
Frank Pallone, Jr., NJ-6  
Bart Gordon, TN-6  
Bobby Rush, IL-1  
Anna Eshoo, CA-14  
Gene Green, TX-29  
Ted Strickland, OH-6  
Diana DeGette, CO-1  
Lois Capps, CA-23  
Tom Allen, ME-1  
Jim Davis, FL-11  
Tammy Baldwin, WI-2  
John Dingell, MI-15 (ex-officio)

## **Senate Health, Education, Labor and Pensions (HELP) Committee**

### **Republicans**

Mike Ensign, WY (Chairman)  
Judd Gregg, NH  
Bill Frist, TN  
Lamar Alexander, TN  
Richard Burr, NC  
Johnny Isakson, GA  
Mike DeWine, OH  
John Ensign, NV  
Orrin Hatch, UT  
Jeff Sessions, AL  
Pat Roberts, KS

### **Democrats**

Edward Kennedy, MA  
Christopher Dodd, CT  
Tom Harkin, IA  
Barbara Mikulski, MD  
James Jeffords, VT  
Jeff Bingaman, NM  
Patty Murray, WA  
Jack Reed, RI  
Hillary Rodham Clinton, NY

# LOBBY DAY LINGO: A GLOSSARY OF TERMS

## Lobby Day 2005

Many of the terms you'll hear at training and in your meetings may be unfamiliar at first. This glossary may be a useful reference for you. Italics indicate that a definition for this term is also included in the glossary.

**Appropriations:** The annual process used by Congress to divide up the approved budget for the federal agencies to spend. Appropriations legislation begins on the *House* side. The *Senate* also develops its own bills and differences are worked out at *conference*. Appropriations subcommittees have authority to develop spending bills that relate to various domestic and foreign programs. The Labor, Health and Human Services, Education and Related Agencies (LHHS) Appropriations Bill is the largest of the bills; it directs spending for federal research and health programs, along with a wide array of other visible programs.

**Appropriators** (see Appropriations): Members of Congress who serve on the *committees* and subcommittees that determine federal spending.

**Authorizers** (see Reauthorization): Members of Congress who serve on the *committees* and subcommittees that establish structure and direction for federal agencies.

**Centers for Disease Control and Prevention (CDC):** The federal agency charged with protecting the public's health. Unlike most federal agencies, CDC is headquartered in Atlanta. Dr. Julie Gerberding is director of the CDC. Its CFS program has benefited from the restoration of \$12.9 million that was funneled to other programs between 1995 and 1998. Dr. William Reeves is CDC's lead CFS researcher.

**CFSAC** (see Chronic Fatigue Syndrome Advisory Committee)

**Chronic Fatigue Syndrome Advisory Committee (CFSAC):** The federal advisory committee established by the *Department of Health and Human Services* to provide guidance for policies and programs that affect CFS and people with CFS.

**Committees:** Congress has dozens of committees to handle issues of domestic and foreign importance to the country. Members of Congress serve on multiple committees; their committee membership often reflects personal interests, as well as the interests of their constituency. The listing of committee members closely aligns with their seniority on that committee, making those at the top of the list often more experienced and influential on the committee. The number of Republicans and Democrats on a committee is determined by the relative number of each party then serving in that house of Congress.

**Conference:** The process used by the *House* and *Senate* to work out differences in their versions of the same bill. This takes place after the *House* and *Senate* have each moved their own bills from the subcommittee, to the full *committee* and then to the *floor* with a passing vote. After conference, the bill goes to the full *House* and full *Senate* for approval. Once approved, it goes to the President for his signature or a veto.

**Department of Health and Human Services (DHHS):** Part of the Executive Branch under the President's authority, this department carries out policy and programs that relate to health and service delivery. The *NIH*, *CDC*, Food and Drug Administration and several other agencies report to DHHS.

**Delegation:** All the representatives and two senators from a given state.

**Earmark:** A funding amount for a specific program set by Congress in an *appropriations* bill. In 1994 Congress moved away from "earmarking" funds for all but a relative few programs. You will often hear reference to this policy when making requests for a specific funding level for CFS research. It is a very standard response for members and staff alike to use in discussions with advocates.

**Fiscal Year (FY):** The government's accounting year that runs from October 1 to September 30.

**Floor:** Often used in describing the process of how a bill becomes a law. A bill is said to "go to the floor" when it's time for all members of the *House* or *Senate* to vote on it.

**House of Representatives:** The lower house of Congress populated by 435 members elected every two years (even years – 2004, 2006, etc.). Each state's representation in the House is determined by its population. For example, Rhode Island has just one member of Congress while New York has 29 U.S. representatives.

**Language** (see Report Language)

**Lobby:** The act of persuading someone to take a specific action. There are legal limits on how much lobbying not-for-profit organizations can do without risking their charitable status. The formal definition of lobbying specifies that the organization must be attempting to influence a particular bill or policy. In the case of Lobby Day, much of what we do is educating members of Congress about CFS and how policies impact those with CFS. The Association stays well within the accepted limits of lobbying activity.

**Majority:** The party holding the largest number of seats in either the *House* or *Senate*. In the 109<sup>th</sup> Congress, Republicans are in the majority in the House and Senate and therefore have more members on all of the *committees* and also control the chairmanship of these committees.

**Mark-up:** The process used by *committees* and subcommittees to develop bills. This term also refers to the meetings held by *committees* to establish priorities and actually write legislation.

**Minority:** The party holding the second greatest number of seats in either the *House* or *Senate*. Democrats are currently in the minority in both houses of Congress.

**National Institutes of Health (NIH):** An agency of the *Department of Health and Human Services* that supports most of the federally sponsored biomedical research. NIH is made up of 27 individual institutes and offices. It is headquartered in Bethesda, Maryland and its director is Dr. Elias Zerhouni. CFS research is coordinated across NIH

by the Office of the Director under guidance of the Office of Research on Women's Health (ORWH).

**PA** (see Program Announcement)

**Prevalence:** The number of people who have a certain medical condition or disease at a given time. The prevalence of CFS in the U.S. is estimated to be at least 800,000.

**Program Announcement:** A statement of interest issued by the *NIH* to the research community inviting proposals in an area of science/medicine. Applicants compete for funding against all others submitting proposals in response to all of *NIH's* PAs.

**Ranking Member:** The most senior member of the *minority* party on a congressional *committee*.

**Reauthorization:** A process used by Congress to develop laws that provide structure and authority to an agency. Most authorization bills are written and passed for a period of several years. Congress is currently working on reauthorizing the *NIH*. A host of sensitive political issues have derailed the process several times in the past few years. The last *NIH* Reauthorization bill was signed into law in 1993 by President Clinton.

**Request for Applications (RFA):** A special statement of interest issued by the *NIH* to the research community inviting proposals and providing funds for applications that meet rigorous review standards. Researchers are more attracted to RFA announcements because *NIH* indicates a financial commitment to this area of study through an RFA, as opposed to a *PA*.

**RFA** (see Request for Applications)

**Report Language:** Specific directions given by Congress in conjunction with *appropriations* bills. Since Congress will not *earmark* funds for specific programs ("\$10 million for CFS"), they use report language to convey their priorities for the use of funds. While report language is not "law," agencies understand that Congress states its intentions through this report and generally comply with such direction. We will be asking members of Congress to use our recommended language in the LHHS Appropriations Report.

**Secretary for Health:** The top official appointed by the President to lead the *Department of Health and Human Services*. Mike Leavitt is the current Secretary for Health. He took this post in late 2004, replacing Tommy Thompson. Leavitt is the former governor of Utah. Prior to serving as Secretary for Health, he was the director of the Environmental Protection Agency. Secretary Leavitt has no direct background in health or medicine.

**Senate:** The upper house of Congress populated by 100 members, each elected for six-year terms. There are two members of the Senate for every state, giving all states equal representation. Their terms are staggered so that approximately one-third of the Senate is elected every two years.



# 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.** CFIDS 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 Communications, by phone at 704-364-0466 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 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 Communications, Marcia Harmon, at 704-364-0466 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 Communications, at 704-364-0466, or e-mail to [mlharmon@cfids.org](mailto: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<sup>th</sup>.
- **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. If you would like more specific information or help in deciding how to approach your local media, please call Marcia Harmon, Director of Communications, at 704-364-0466 or e-mail to [mlharmon@cfids.org](mailto:mlharmon@cfids.org).*

- **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 Communications 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, 2005 will be the eleventh 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 recent 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 at  
704-365-2343 or visit [www.cfids.org](http://www.cfids.org).