

THE CFIDS ASSOCIATION OF AMERICA

May 12 - International CFIDS Awareness Day Information Packet

Enclosed in this packet you will find:

- **Guidelines for May 12th Activities**
How to get involved in advocacy, media and other efforts
- **Advocacy Instructions**
Sample advocacy letter
Sample proclamation
- **Media Instructions**
Additional media “tips”
Suggestions for public awareness activities
Sample media letter
May 12th press release
- **Letter Writing Campaign Enclosure**
CFIDS fact sheet
- **Lobby Day Information**
- **Sample CFIDS Information Card**
These cards (item #6091) are available in packs of 20. For ordering information please call the Resource Line, 704-365-2343

**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

Web site: <http://www.cfids.org>

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

Guidelines for May 12th, International CFIDS Awareness Day

PWCs, their families and friends are encouraged to educate others about the legitimacy and reality 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.
- 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, if they have difficulty writing, 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 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.
- Have a CFIDS Awareness Day Proclamation issued (see enclosed information).
 - Start this process early! Thirty days are required to complete the document.

If writing is difficult...

- Use the enclosed sample letter "as-is" or as a guide for a more personal letter.
- 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 number, 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 2002.
 - 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 the Association's Resource Line, 704-365-2343, and request an information packet be sent to them.
- Designate someone as your group's spokesperson, so the media has a contact for stories.

**** continued on next page ****

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, Monday through Thursday 9am to 5pm and Friday 9am to 1pm EST.

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 the Resource Line at 704-365-2343. Please remember, this display does not need to be "manned" by someone from your group.
- If members of your support group can handle 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 at 704-365-2343, Monday through Thursday 9am to 5pm and Friday 9am to 1pm EST.
- The CDC's CFS booklet is available at no charge to all requesting a copy and is a good tool for educating practitioners. For multiple copies of this resource, write to CDC, Attn: CFS, 1600 Clifton Road, Mail Stop A15, Atlanta, GA 30333; or call 404-639-3532. When ordering, please refer to the "CDC's CFS May 1999 booklet."
- 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 complementary practitioner subscriptions, call the Resource Line at 704-365-2343.

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, 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 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 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 federal Senators
 - Your Governor
 - Your state Representative
 - Your state Senator
 - Your Mayor
- Discuss and assemble proposed language that you would like included in the proclamation (see suggestion on the back of this sheet). 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.
 - Make the appointment.
 - 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 the requirements of 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 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 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 hundreds of thousands of 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 as CFIDS Awareness Day and applauds the efforts of those battling the illness;

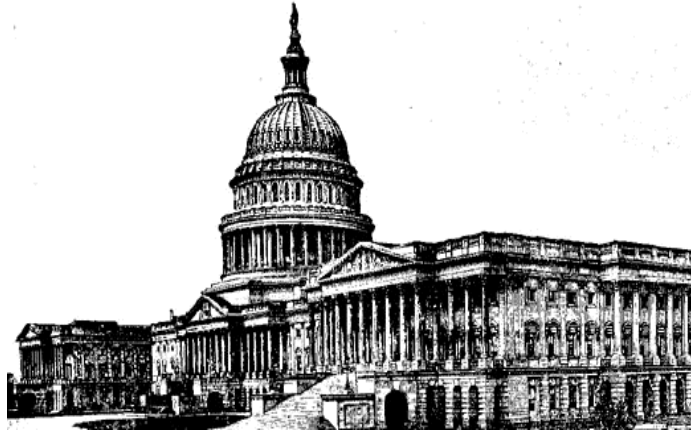
And directs that a copy of this citation, sponsored by [your elected official] be prepared for the CFS Association of the Lehigh Valley.*

**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 INSTRUCTIONS

May 12 is
International CFIDS/ME Awareness Day:
Tell Congress That You Are Concerned About
CFIDS

Advocacy Alert

In 1993, the CFIDS community identified May 12th 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.

What to do:

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).

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. You can use the sample letter included in this section as a starting point or 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.

Given persistent problems with delayed mail service in Washington following the Anthrax scares, this year 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 so your letter will not be considered a potential Anthrax threat.

When addressing your letter, use the following format:

Senators:

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

Dear Senator (Last Name):

(Body of letter)

Sincerely,

(Your name and mailing address)

Representative:

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

Dear Representative (Last Name):

(Body of letter)

Sincerely,

(Your name and mailing address)

If you get a response from a Member of Congress, please let us know. You can write to The CFIDS Association of America, PO Box 220398, Charlotte, NC 28222-0398; call 704-365-2343; fax 704-365-9755; or e-mail cfids@cfids.org. Send us copies of letters and e-mail messages you receive, if you can.

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 **Labor, Health and Human Services, Education and Related Agencies (L/HHS) 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
C.W. Bill Young, Florida
Ernest J. Istook, Jr., Oklahoma
Dan Miller, Florida
Roger F. Wicker, Mississippi
Anne Northup, Kentucky
Randy "Duke" Cunningham, California
Kay Granger, Texas
John E. Peterson, Pennsylvania
Don Sherwood, Pennsylvania

Democrats:

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

Senate L/HHS Appropriations Subcommittee:

Democrats:

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

Republicans:

Arlen Specter, Pennsylvania - Ranking Minority Member
Thad Cochran, Mississippi
Judd Gregg, New Hampshire
Larry Craig, Idaho
Kay Bailey Hutchison, Texas
Ted Stevens, Alaska
Mike DeWine, Ohio

House 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
Greg Ganske, Iowa
Charlie Norwood, Georgia
Barbara Cubin, Wyoming
Heather Wilson, New Mexico
John B. Shadegg, Arizona
Charles W. "Chip" Pickering, Mississippi
Ed Bryant, Tennessee
Robert L. Ehrlich, Jr., Maryland
Steve Buyer, Indiana
Joseph R. Pitts, Pennsylvania
W.J. "Billy" Tauzin, Louisiana

Democrats:

Sherrod Brown, Ohio - Ranking Minority Member
Henry A. Waxman, California
Ted Strickland, Ohio
Tom Barrett, Wisconsin
Lois Capps, California
Ralph M. Hall, Texas
Edolphus Towns, New York
Frank Pallone, Jr., New Jersey
Peter Deutsch, Florida
Anna G. Eshoo, California
Bart Stupak, Michigan
Eliot L. Engel, New York
Albert R. Wynn, Maryland
Gene Green, Texas
John D. Dingell, Michigan

Senate Health, Education, Labor and Pensions (HELP) Committee:

Democrats:

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

Republicans:

Judd Gregg, New Hampshire - Ranking Minority Member
William Frist, Tennessee
Mike Enzi, Wyoming
Tim Hutchinson, Arkansas
John Warner, Virginia
Christopher Bond, Missouri
Pat Roberts, Kansas
Susan Collins, Maine
Jeff Sessions, Alabama
Mike DeWine, Ohio

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). Over 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. Persons 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, treatment and a cure. In a recent survey fielded to more than 8,100 medical professionals and researchers from a variety of disciplines, 77% felt that the amount of professional education about CFIDS is not adequate and 87% 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. For more information, please contact The CFIDS Association of America's Washington, D.C. representatives at telephone number 202-628-7770 or e-mail at advocacy@cfids.org. Please help us increase awareness of CFIDS by recognizing May 12 as International CFIDS Awareness Day. Thank you for your consideration of these important matters.

Sincerely,



MEDIA INSTRUCTIONS

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

Media Alert

To assist with your efforts in working with members of the media, a sample media letter and a May 12th press release are included in this section of the May 12th Awareness Day information packet. Here are recommendations for the most effective use of the materials:

- **Sample Media Letter** - Use this letter, along with the CFIDS Fact Sheet, to inform and educate new media contacts. 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. Or if you prefer, you may use this letter as a guide for your own letter. 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.
- **May 12th News Release** - This news release, along with the CFIDS Fact Sheet, should be sent to media contacts with whom you or your group have already established relationships. The news release can be used as is by filling in your group's designated contact beside "Contact" and his/her phone number beside "Phone number." Most reporters will prefer to cover a story from the local angle so it's important to provide a local contact. It might be helpful to include a personal note reminding the reporter of your past relationship and offering to provide additional information if needed.
- **Medical Professionals Survey Fact Sheet** - If your local media are looking for a new "hook" for CFIDS coverage, try The CFIDS Association's medical professionals survey. The attached survey fact sheet can be sent to reporters along with the sample media letter or news release. For more information, check out the Association's on-line survey media kit at <http://www.cfids.org/resources/cpr-mediatools.asp>.

Also included are tips for dealing with the media and more suggestions for public relations activities surrounding CFIDS Awareness Day. If you would like more specific information or help in deciding how to approach your local media, we encourage you to contact Renee Brehio, the Association's Director of Communications by phone at 704-364-0466 or by e-mail at rmbrehio@cfids.org, or you can contact Leah Moseley at 704-364-0016 or lmoseley@cfids.org.

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 Renee Brehio, Director of Communications, at 704-364-0466 or e-mail to rmbrehio@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 Renee Brehio, 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 in advance to ask if he or she minds being referred press calls in case the reporter wants to interview a medical expert. Remember that you can always refer 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 in the recent past. 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.

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 Renee Brehio, Director of Communications, at 704-364-0466, or e-mail to rmbrehio@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 for suggestions), or you can Xerox 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 who would be 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.

Dear

May 12, 2002 will be the tenth 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. Please help us educate health care consumers about this debilitating condition by reporting about CFIDS on or around May 12.

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% 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 toll-free number (800-442-3437) and a Web site (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,

NEW SURVEY REVEALS CHRONIC FATIGUE AND IMMUNE DYSFUNCTION SYNDROME (CFIDS) IS AS DISABLING OR DEBILITATING AS LUPUS, MULTIPLE SCLEROSIS AND RHEUMATOID ARTHRITIS

CFIDS Awareness Day Provides Opportunity for Education

A recent survey fielded by The CFIDS Association of America to more than 8,100 medical professionals and researchers revealed that three-quarters believe CFIDS is as or more disabling than other chronic diseases such as lupus, multiple sclerosis or rheumatoid arthritis. Seventy-seven percent of survey respondents feel that the amount of professional education about CFS is not adequate and that more is needed. And, 87% of respondents indicated a need for more funding for CFIDS research.

May 12, 2002 is the tenth annual International Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) Awareness Day, and advocates are spreading the word that CFIDS is a serious, complex medical condition that deserves greater recognition and study. More than 800,000 Americans suffer from CFIDS, which is often misunderstood and misdiagnosed.

“The CFIDS Association’s survey findings confirm that CFIDS is increasingly being recognized as a severely debilitating illness, but medical professionals still lack the core knowledge and tests they need to diagnose it quickly and accurately,” says Kim Kenney, Association President and CEO. “Much has been learned about CFIDS, but it is now very apparent that more research and education is needed.”

Individuals from around the world who suffer from CFIDS will be conducting educational activities on May 12. With an increasing number of advocates participating each year, patients, family members, and friends are making an impact by communicating to their congressmen and communities about how this illness destroys lives.

There is no known cure for CFIDS, which also is called chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME). Symptoms include debilitating fatigue that is not improved by bed rest and may be worsened by physical or mental activity, impairment of short-term memory or concentration, sore throat, tender lymph nodes, muscle and joint pain, and headaches. Symptoms must be present for more than six months without any other medical explanation. Individuals with CFIDS function at a substantially lower level of activity than before onset of the illness, and many are unable to continue holding jobs, attending school, or caring for themselves or family members.

Individuals who would like more information on CFIDS can call The CFIDS Association of America toll-free, 24-hours a day, at 1-800-442-3437, or visit the Association’s Web site at www.cfids.org. Media can call the Association’s Director of Communications at 704-364-0466 for more information or to arrange interviews.

MEDICAL PROFESSIONAL SURVEY ON CFS

KEY FINDINGS

- **75%** of survey respondents believe that CFS, also known as CFIDS, is at least **as disabling (53%)** or **more disabling (22%)** than other chronic diseases such as lupus, multiple sclerosis or rheumatoid arthritis.
- According to half of the respondents, **lack of a diagnostic test** is the greatest barrier to accurately diagnosing CFS. **35%** feel the greatest barrier is lack of a known cause and **31%** said it is due to lack of knowledge about CFS in the medical community.*
- **68%** of physicians surveyed said they use **patient history** to arrive at a CFS diagnosis. **72%** **exclude other common causes** for symptoms, **10%** use diagnostic procedures such as tilt table testing and **25%** rely on lab tests.
- **69%** of respondents answered that it is possible to make a **diagnosis in children 12 and over**, while only **18%** believe you can diagnose CFS in children **age 5 to 12**.
- No one cause was cited by a majority of respondents as the primary cause of CFS. The largest group, **37%**, believe the primary cause of CFS is **immune dysfunction**, while an almost equal number, **33%**, said that the cause is unknown.
- **83%** cited **impaired memory or concentration** as the most common non-fatigue related symptom in CFS patients.
- **40%** said there was a symptom other than fatigue that made them more likely to suspect CFIDS or without which they would not make a diagnosis. The most common answer was **post-exertional malaise**, which is incapacitating fatigue lasting more than 24 hours after physical or mental exhaustion.
- In terms of treatment, the largest percentage of respondents (**69%**) counsel patients on making **lifestyle adjustments**, while smaller percentages also prescribe treatments for the various symptoms of CFS such as antidepressants, sleep aids, nutritional supplements, pain medication, immune modulators, antivirals or antibiotics and cardiovascular or blood pressure drugs.
- **77%** of the medical professionals feel that the amount of **professional education** about CFS is **not adequate** and that more is needed.
- **87%** of respondents indicated a need for **more funding** for CFS research.
- Approximately half of the respondents (**57%**) feel the general public is **not very well informed** about CFS. **11%** thought that the public is somewhat informed and **0%** feel that the public is **well informed**. **32%** actually feel the public is **somewhat to very misinformed about CFS**.

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**(Note: some statistics equal more than 100% due to multiple answers provided by respondents)*

Individuals who would like more information on CFIDS can call The CFIDS Association of America toll-free, 24-hours a day, at 1-800-442-3437, or visit the Association's Web site at www.cfids.org. Media can call the Association's Director of Communications at 704-364-0466 for more information or to arrange interviews.



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

CFIDS is recognized by the National Institute of Health (NIH), Centers for Disease Control (CDC), Food and Drug Administration (FDA) and Social Security Administration (SSA) as a serious, often disabling illness. It is marked by unrelenting exhaustion, muscle pain, cognitive disorders that patients call "brain fog," and a myriad of other physical symptoms.

Some patients are bedridden; others consider themselves fortunate if they can work or attend school at least part time, since any exertion typically worsens their symptoms. Many are denied disability insurance benefits because doctors and employers believe they are lazy or have a mental illness rather than a serious physical condition.

Research is being done on many fronts, from cardiology to immunology to endocrinology, but the disease remains a mystery. Even the most promising treatments seem to work only for some patients and improve their lives by only small degrees. Following are some facts that are known about CFIDS.

DIAGNOSIS:

- According to the US Centers for Disease Control*, CFIDS is a syndrome characterized by fatigue that is: medically unexplained; of new onset; of at least six months' duration; not the result of ongoing exertion; not substantially relieved by rest; and causes a substantial reduction in previous levels of occupational, educational, social or personal activities. *(*Annals of Internal Medicine*, 1994;121:953-59.)
- The fatigue must be accompanied by four or more of the following symptoms: impaired memory or concentration; sore throat; tender neck or armpit lymph nodes; muscle pain; headaches of a new type, pattern or severity; unrefreshing sleep; post-exertional malaise lasting more than 24 hours; and multi-joint pain without swelling or redness.
- Physicians must exclude other causes of the symptoms prior to making a diagnosis of CFIDS. Conditions that would exclude a diagnosis of CFIDS include other medical disorders known to cause fatigue, primary major depressive illness, medication that causes fatigue as a side effect and alcohol or substance abuse.

PREVALENCE:

- A new study by DePaul University estimates CFIDS at approximately 422 per 100,000 persons in the U.S. This means as many as 800,000 people nationwide suffer from the condition.
- 90% of patients have not been diagnosed and are not receiving proper medical care for their illness.
- Few studies of CFIDS in children and adolescents have been published. It is well accepted that adolescents get CFIDS, although less frequently than adults.
- Research has shown that CFIDS is about three times as common in women (522/100,000) as men, a rate similar to that of many autoimmune diseases, such as multiple sclerosis and lupus. To put this into perspective, CFIDS is over four times more common than HIV infection in women (125/100,000), and is considerably higher than a woman's lifetime risk of getting lung cancer (63/100,000).
- CFIDS has been shown to affect persons of all races, ages and socioeconomic groups.

SYMPTOMS:

- Symptoms include fatigue, substantial impairment of short-term memory or concentration, sore throat, tender lymph nodes, muscle and joint pain, headaches, unrefreshing sleep, and fatigue lasting more than 24 hours following exertion.
- CFIDS is diagnosed when these symptoms persist for more than six months and cannot be explained by any other medical or psychological condition (see "Diagnosis").
- Many veterans of the Persian Gulf war have a symptom complex that has been determined by scientists to be virtually identical to CFIDS.

RECOVERY:

- The clinical course of CFIDS varies widely. Some patients recover to the point that they can resume work and other activities, even though they continue to experience symptoms.
- According to the CDC, the probability of significant improvement in CFIDS patients was 31.4% during the first five years of illness and 48.1% during the first 10 years. However, even "recovered" patients stated that they continued to have some CFIDS-defining symptoms (*Journal of Chronic Fatigue Syndrome*, 1999: 5 (1) 17-27).

TREATMENT:

- Treatment of CFIDS is aimed at symptom relief. No single therapy exists to help all patients with CFIDS.
- Lifestyle changes, including increased rest, reduced stress, dietary restrictions, nutritional supplementation and minimal exercise are frequently recommended.
- Only one drug to treat CFIDS, Ampligen, is nearing the end of the FDA's approval process.

THE CAUSE:

- Despite an intensive decade-long search, the cause of CFIDS remains unknown. Many different viruses, bacterium, toxins and psychological causes have been considered and rejected, but the search continues.
- Genetic and environmental factors may play a role in developing and/or prolonging the illness, although increased research is needed.

THE NAME:

- The name "chronic fatigue syndrome" was coined in 1988 by a group of scientists.
- The Department of Health and Human Services Chronic Fatigue Syndrome Coordinating Committee (CFSCC), which is composed of representatives from the patient advocacy and medical communities as well as federal agencies conducting research, is addressing the need to change the name.
- The name "chronic fatigue syndrome" is believed by most patients and researchers to be unacceptable, as it focuses too heavily on only one easily misunderstood symptom of the illness. Thirty years ago, multiple sclerosis patients were subject to this type of stigma -- people then called MS "hysterical paralysis."
- CFIDS is also known as chronic fatigue and immune dysfunction syndrome (CFS), myalgic encephalomyelitis (M.E.) and by many other names.

GOVERNMENT RESPONSE:

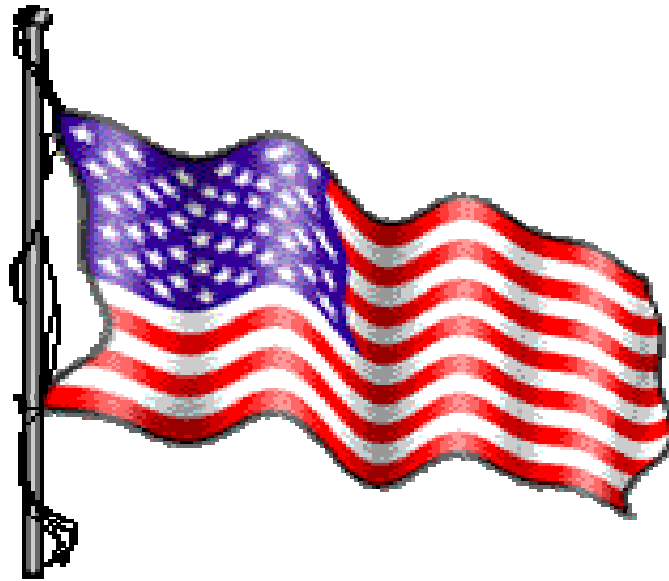
- Ever since CFIDS was recognized as a public health concern in the mid-1980s, Congress has urged federal health agencies to allocate increasing resources to the investigation of CFIDS. Although the true amount of spending is in question, the major public health agencies have reported to Congress a 400% increase in CFIDS spending over the last six years.
- SSA has issued guidelines for determining disability benefits for persons with CFIDS. This recognition of CFIDS as a potentially disabling condition is a major step forward for those patients who can no longer work as a result of the illness.
- The CFIDS Association of America has been working since 1992 to secure a more dedicated response to CFIDS from the federal government. Its grassroots advocacy program, C-ACT, encourages patients and those who care for them to get involved in efforts to increase scientific knowledge about CFIDS.

ABOUT THE CFIDS ASSOCIATION OF AMERICA:

- The CFIDS Association of America is the leading organization dedicated to conquering CFIDS and related disorders. Since 1987, the Association has invested over \$3.3 million in CFIDS research.
- The Association's publication, *The CFIDS Chronicle*, is the world's most authoritative and widely read source of information about CFIDS.

Individuals who want to know more about CFIDS can call The CFIDS Association of America's toll-free number 24-hours a day (800/442-3437) or visit its Web site at www.cfids.org.

6/1/01



**LOBBY DAY
WASHINGTON, DC**

Lobby Day Washington, DC

Personal contact from voters who care about CFIDS is the secret weapon in the CFIDS advocacy arsenal. To facilitate contact with elected officials, The CFIDS Association of America sponsors an annual Washington, D.C. Lobby Day event.

Each year, CFIDS advocates from around the country, including persons with CFIDS (PWCs) and their family members and friends, come together on Capitol Hill on a single day to travel the halls of Congress and personally educate our nation's leaders about CFIDS and ask for help in securing an improved federal response to the illness.

Lobby Day participants are trained on effective meeting strategies and provided with materials to share with elected officials so they will feel confident and prepared before their first meeting.

This year's Lobby Days are being held on March 20-21. For more information on Lobby Days 2003, contact the Association by e-mail at advocacy@cfids.org, or write to The CFIDS Association, Attn: 2003 Lobby Day Information, PO Box 220398, Charlotte, NC 28222-0398.

Even if you can't make it to Lobby Day, there are several things you can do locally to make Congress aware of the vast number of people who are concerned about CFIDS. See the Advocacy section of this Awareness Day packet for sample letters and ideas for building knowledge of CFIDS on Capitol Hill.