

# Lend us your voice!

## Make your opinions count!

### Participate in CFIDS Lobby Day!

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

Plans for the CFIDS Association's **2006 Lobby Day** are under way. Make sure your congressional representatives hear the message about CFIDS — that it is **real**, it is **serious** and it warrants increased **attention and funding** — by participating in this year's event. Newly elected members of Congress, members of funding committees and representatives from your state need to understand the impact CFIDS has on their constituents and the communities they represent.

A mandatory training session on Monday afternoon, **May 8, 2006** will prepare you to effectively share your CFIDS experience — or that of a friend or family member — with congressional staff members so that they can share the message with congressional leaders.

On **Lobby Day**, Tuesday, **May 9**, we will work in state delegations to carry our message to the halls of Congress and into the offices of key legislative decision-makers — the people who determine how much money federal health agencies will receive and what agency officials will be told Congress expects from them.

Please help to make your congressional representatives more responsive to CFIDS as an important public health concern by participating in Lobby Day 2006 in Washington, D.C. Full details and a registration form are enclosed. For further information, contact the CFIDS Association of America (telephone: 704-365-2343, e-mail: [LobbyDay@cfids.org](mailto:LobbyDay@cfids.org), fax: 704-365-9755).

*Lobby Day was so organized. I couldn't have been more impressed. The color-coded materials, the training, the meeting logistics – it was the most professionally run thing I've ever seen. I'd do it again because, overall, it was very empowering. It was good to be there, not just as a person who is ill with CFIDS, but as a U.S. citizen exercising her right to be heard.*

— Tamara Balsamides  
New Jersey

*I've had CFIDS since 1985, although it wasn't diagnosed until 1996. I feel like it was important to be there so legislators could see people who look like a cross-section of America who are affected by this illness. And it was important to see men, who often don't step forward and admit they have a chronic illness. I was there to educate and advocate, and to paint a picture they could emotionally connect to. I tried to be conversational and build a relationship with people we met with on Capitol Hill.*

— Hosiah Huggins  
Ohio

# Lobby Day 2006 Information

Please join the CFIDS Association of America for the 2006 Washington, D.C. CFIDS Lobby Day Training and Capitol Hill Visits on Monday and Tuesday, May 8-9. To register, please complete and return the enclosed registration form by Monday, April 17.

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

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

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

<b>Friday, April 7</b>	<b>Deadline for making hotel reservations at the Holiday Inn Central</b> (see below)
<b>Monday, April 17</b>	<b>Registration form due at the CFIDS Association of America</b> Your timely response helps us better utilize your time while in D.C.
<b>Friday, April 28</b>	<b>Preparation materials mailed to all Lobby Day participants</b>
<b>Monday, May 8</b> 1:00-5:00 pm	<b>Mandatory Lobby Day Training Session</b> Holiday Inn Central, 1501 Rhode Island Ave., NW, Washington, D.C.
<b>Tuesday, May 9</b> All Day	<b>Capitol Hill Visits (Lobby Day)</b> Schedules will be distributed at the afternoon training session. <i>Please do not make your own appointments -- we will contact members of Congress on your behalf to arrange meetings.</i>
5:30 pm	<b>Lobby Day Wrap-Up Party</b> Lobby Day participants are invited to a post-Lobby Day celebration at Tom Sheridan's home to share the day's experiences and achievements.

## ***Hotel Information***

### ***Holiday Inn Central***

***1501 Rhode Island Ave. NW, Washington, DC 20005***

***Phone: 202-483-2000***

Group rate reservations **must** be made **by 5:00pm on April 7**. Room rate: \$159 (plus tax) per night. To make your reservations, call Mary Stallings at 202-349-3027, **mention group code "CFIDS" to get the group rate** and provide credit card number to guarantee your room.

**Please complete and return the attached Registration Form no later than Monday, April 17, 2006 to the mailing address or fax number below.**

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

# 2006 Lobby Day Registration Form

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

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

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

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

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

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

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

## In Washington, I will be staying:

At the Holiday Inn Central (call Mary Stallings at **202-349-3027** by April 7: use code "CFIDS")

At home or other accommodations:

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

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

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

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

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

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

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

## Meeting preferences and information:

Each meeting typically lasts 10 to 20 minutes. We will assign appointments based on advocates' home states and congressional committee assignments. *Please do not schedule your own appointments*. We will try to accommodate your preferences (noted below), but we can't guarantee them, as we are dependent upon the availability of congressional members and staffers on May 9.

## Please schedule me on May 9 for (please check all that apply):

Morning appointments on Capitol Hill

Afternoon appointments on Capitol Hill

A maximum of 3 meetings (light schedule)

A maximum of 9 meetings (heavy schedule)

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

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

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

(continued)

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

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

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

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

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

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

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

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

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

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

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

*Return this form no later than Monday, April 17, 2006 to:*

**The CFIDS Association of America, Inc.**

6827 Fairview Rd., Suite A, Charlotte, NC 28210

Phone: 704-365-2343; Fax: 704-365-9755; E-mail: LobbyDay@cfids.org

**Additional Information**

**Media contacts**

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

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

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