

The CFIDS Association of America

Working to conquer chronic fatigue and immune dysfunction syndrome

Choosing a Health Care Provider *Fact Sheet*

It's important that people who have, or think they may have, chronic fatigue syndrome (CFS, also known as chronic fatigue and immune dysfunction syndrome or CFIDS) receive appropriate and timely medical care. There is some evidence to indicate that the sooner a person is treated, the better the chance of improvement.

Yet finding a health care provider (HCP) who is knowledgeable about CFS can be a challenge. Only a handful of physicians specialize in the treatment of CFS and many medical professionals remain skeptical of the illness. Fortunately more and more providers are educating themselves about CFS and seeking the information and tools that will help them provide a higher level of care to their CFS patients.

The CFIDS Association of America developed this fact sheet to help you in your search for a CFS-knowledgeable physician or other health care professional.

Start your search

Begin with **your primary care provider**. If you already have a good relationship with a health care provider, encourage him/her to learn more about CFS. (See "Educate your Health Care Provider" below)

CFS support groups may be able to help you in your search for a local health care provider in your area.

Talk to **other people with CFS, friends, relatives, neighbors, co-workers, nurses**, keeping in mind that most are not qualified to characterize a doctor as competent or incompetent. However, compassion, a good "bedside manner" and an open mind are qualities that count in a health care provider, especially when treating a chronic illness like CFS.

Gather Information

Before you contact the health care providers you're interested in, collect some basic information about their education, credentials and qualifications. Are they licensed? Are they board certified? Have they ever been sued for malpractice? At which hospital(s) do they have privileges? Are they in your insurance plan? Do they accept Medicaid/Medicare (if applicable)? For information on health care professionals, such as licensure status and board certification, see the "Information Resources" section.

Give Them a Call

Phone the offices of the providers who meet your criteria and speak with the office managers and try to gauge their feelings about CFS. You might say, "I have (or think I may have) CFS and am looking for a health care provider. Is the doctor familiar with CFS? Does he or she diagnose CFS? How many CFS patients does he or she have?" It's a good idea to write down all your questions before calling and to make note of their answers for reference later.

Educate your Health Care Provider

Let your health care provider know that the CFIDS Association is a credible source of CFS information. Your provider can obtain materials covering everything from basic diagnostics, to treatment strategies, to the very latest in CFS research. For more about Association-led efforts to enhance understanding of CFS among health care providers nationwide and to deliver reliable information on diagnosis and treatment, visit www.cfids.org/treatcfs.

Information Resources

Local libraries and physician referral services (available through your hospital or health insurance provider) can help you gather background information about HCPs. Professional organizations are also a valuable source of information about providers' educational backgrounds, licensure status, areas of medical specialty and board certification, items that may aid you in your decision-making process. You may wish to contact:

American Medical Association (AMA)

Department of Physician Data Services

515 N. State Street

Chicago, IL 60616

Web site: <http://webapps.ama-assn.org/doctorfinder/html/patient.html>

Through the AMA you can find out about a doctor's educational background and areas of medical specialty and whether or not the doctor is a member of the AMA. You can also check the *American Medical Association Medical Directory* at your local public library or book store.

American Board of Medical Specialties

47 Perimeter Center East, Suite 350

Atlanta, GA 30346

800/776-2378

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

This organization will tell you whether a doctor is board certified or board eligible in a particular area. "Board certified" means the doctor has completed two additional years of training and passed a national examination. "Board eligible" means that the training, but not the test, has been completed.

National Commission on Certification of Physicians Assistants

Web site: <http://www.nccpa.net>

National Council of State Boards of Nursing

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

The National Council of State Boards of Nursing has a Web site that links to sites of state boards.

When You Visit Your Provider

Make the most of your office visit by coming prepared. Bring a list of your symptoms and medications – many people with CFS find that keeping a symptom diary is helpful. Bring a list of questions and answer your provider's questions fully. Write things down. To help ensure that you remember and fully understand any instructions you're given, bring a friend or family member with you or even ask permission to audiotape your visit.

Effective communication with your health care provider is crucial to your care. To learn about strategies to enhance the patient-doctor partnership, read "Doc Talk" from the spring 2004 issue of the CFIDS Association's quarterly publication, the *CFIDS Chronicle*.

With thanks to Camilla Cracchiolo, RN; Thomas B. McCall, MD; and K.H. Cherry and Terri Lupton, BSS, RN.

Rev. 9/08

The mission of the CFIDS Association of America is to conquer CFS. To learn more about our initiatives in CFS awareness, education, public policy and research, visit our website at www.cfids.org or contact us by email at cfids@cfids.org, or by phone at 704-365-2343.