

**CFSAC Education Subcommittee report
June 2004**

Education on CFS and chronic fatiguing illnesses has been targeted as number one priority by the CFSAC; and an 8-member education subcommittee was established. The subcommittee has held internal discussions and correspondence exchanges, reviewed resources (printed, web-based, etc.), and summoned the advice and experience of individuals, patient organizations, professional societies, and governmental agencies to:

- Identify and assess past, existing and novel educational strategies;
- Formulate and encourage involvement at individual and organizational levels;
- Invite ideas with experiential substantiation or high likelihood of success/impact;
- Formulate recommendations for consideration by the full CFSAC committee.

Assessment of CFS and CFS-related education

Successes

There is increased awareness, diagnosis and treatment of fatigue in different contexts, such as cancer and autoimmune disease.

Limitations and challenges

70% of primary care physicians are frustrated with CFS care and challenging patient population (source: survey, CFIDS Association, 2003). Inability of CFS educators to fulfill expectations stems from a series of limitations:

Content/format: Paucity of evidence-based treatment guidelines; limited and partially standardized CFS case definition; and limited study of CFS natural course, epidemiology and nosology.

Attrition or limited impact of CFS educators.

Most literature sources too specialized, general, and/or outdated.

CFS is included under restrictive categories, such as Women's Health.

Most professional societies lack CFS education-targeted programs.

Impact/outreach: Most educational activities are focused on physicians and nurses.

Limited number and variety mix of healthcare professionals reached.

For instance, 10% occupational/physical therapists reached.

Web-based activities seem to have better numerical outreach.

Mostly inexistent outcome assessment of CFS educational activities.

Funding: Limited for needs.

Suggested recommendations:

General

Increase funding through governmental agencies (CDC and HRSA) to address four target areas; specific aims have been outlined for each area:

Content: *Raise contextual awareness and use learned lessons in CFS and other diseases.*

Educate on fatigue as a symptom, on its diagnosis and treatment in chronic fatiguing illnesses; educate on CFS and its peculiarities.

Use lessons from pain, nausea, and other symptoms that were previously under-diagnosed and under-treated in the context of both recognized and poorly understood syndromes in different specialties (i.e., cancer, autoimmunity).

Address and raise awareness about the different populations affected by CFS: pediatric, adults, men and women.

Format: Diversify means and emphasize practicality.

Expand on the use of the worldwide web and other communication means.

Place CFS within appropriate disease categories (i.e., chronic disabling conditions, and not concealed under partially appropriate categories).

Generate practical up-to-date publications and reference guides.

Impact: Increase outreach, recruitment, and follow-up.

Take educational programs to diverse settings nationwide (allied health care and legal professionals, reimbursement and disability specialists, etc.).

Recruit interest/help from professional organizations and high impact journals.

Encourage collection of qualitative/quantitative data on impact of funded activities (i.e., professional mix and numbers reached; practice changes).

Funding: Raise need awareness and encourage involvement of others.

Promote joint ventures with the private sector as well as health care specialty groups.

Specific examples

The aims described above can be achieved through expansion of some of the current programs or implementation of new ones. Suggestions include:

Grants to patient organizations, healthcare professionals, professional societies or, preferentially, partnerships among them to update, develop, and run nationwide and community-based CFS-related educational programs targeted at health care professionals, specialized societies, patients, and/or professional training programs. Past examples include conferences organized with well-respected health care professionals and the support of grass-root organizations.

Grants for distribution of new and existing educational materials at local and nationwide levels (i.e., Physician's Manual for the Diagnosis and Treatment of Chronic Fatigue Syndrome distributed by the State of New Jersey to all its licensed physicians).

Grants for biannual live and/or web-based regional and national workshops or ground rounds on diagnosis, management, and treatment of CFS and other chronic fatiguing illnesses (CFS, cancer-related fatigue, autoimmune disease-related fatigue, fatiguing illnesses secondary to toxic exposures, etc). Past examples are the HRSA, NIH, CDC workshops and their web-based resources.

Grants for education programs aimed at raising awareness for detection and intervention of disability among pediatric and adult CFS patients.

**CFSAC Education Subcommittee full report
June 2004**

1. Action taken by CFSAC Education subcommittee:

Education on CFS and chronic fatiguing illnesses was identified as number one priority by the CFSAC; an education subcommittee was established with the following members (in alphabetical order):

CFSAC members

Nancy Butler
Jane Fitzpatrick
Kenneth Friedman
Nelson Gantz
Roberto Patarca (Chairman)
Staci Stevens

CFSAC ad hoc members

Bill Reeves
Bill Robinson

The subcommittee has held internal discussions, reviewed resources (printed, web-based, etc.), and summoned the advice and experience of individuals, professional organizations, and governmental agencies (see Appendices 1-3) to:

- 1.1 Identify and assess the impact of past and existing strategies and the reasons for their success/failure;
- 1.2 Encourage and formulate specific involvement at individual and organizational levels;
- 1.3 Invite ideas with experiential substantiation or high likelihood of success and impact.
- 1.4 Formulate recommendations for consideration by the full CFSAC committee and help in their implementation by making available through CFSAC website all information gathered.

2. Conclusions from assessment of state of CFS education:

- 2.1 *Successes and limitations of CFS educational activities*
Education in CFS and CFS-related conditions has had its successes and limitations; formidable challenges remain:

Successes

Increased awareness of fatigue as an important symptom to diagnose and treat in different contexts, such as cancer and autoimmune disease, among others.

Limitations and challenges

70% of primary care physicians are frustrated with CFS care and challenging patient population (source: survey, CFIDS Association, 2003).

Inability of CFS educators to fulfill expectations for educating peers and students in health care field:

Limitations in content and format

- Need for evidence-based treatment guidelines; standardization of CFS case definition; and further study of CFS natural course, epidemiology and nosology.
- Attrition or limited impact of CFS educators (for one numerical assessment example see Appendix 4).
- Most literature sources too specialized, too general, inconsistent, and/or outdated (examples in Appendix 5).
- CFS is not included in some governmental sites under restrictive categories, such as Women's Health

Limited outreach of educational activities:

- Most educational activities are focused on physicians and nurses (Appendix 6).
- Need to increase number and variety mix of healthcare professionals reached. For instance, 10% occupational/physical therapists reached.
- Web-based educational activities seem to have better numerical outreach (for instance, see Appendix 7).

Limited and in many cases nonexistent appropriate outcome assessment of CFS-related educational activities.

Limited funding for CFS education.

2.2 *Target areas identified*

Four target areas have been identified and specific aims have been outlined for each area:

2.2.1 *Content*

Aim: Raise contextual awareness and use learned lessons. Educate on fatigue as a symptom, on its diagnosis and treatment in chronic fatiguing illnesses, and on CFS and its peculiarities. Use lessons from pain, nausea, and other symptoms that were previously under-diagnosed and under-treated in the context of both recognized and poorly understood syndromes in different specialties (cancer, autoimmune disease, etc.)

2.2.2 *Impact*

Aim: Increase outreach, recruitment, and follow-up.

Take educational programs to diverse settings nationwide (school nurses and teachers, healthcare/reimbursement specialists, legal, etc.).

Recruit interest/help from professional organizations and high impact journals.

Implement means to collect qualitative/quantitative data on impact of funded activities.

2.2.3 *Format*

Aim: Diversify means and emphasize practicality.

Expand on the use of the worldwide web and other information communication means. Properly place CFS within web sites (i.e., not only under Women's Health or concealed under another category).

Generate practical publications and reference guides.

2.2.4 *Funding*

Aim: Raise need awareness and increase level of funding.

Involve both private and public sectors as well as diverse specialties.

Fund both national and regional groups.

3. **Recommendations:**

3.1 *General*

Increase funding through governmental agencies (CDC and HRSA) to address the content, impact and format limitations of current activities by:

expanding current activities beyond their current impact realm;

developing and implementing new educational programs, services and resources for both healthcare professionals and patients.

Grantees must provide outcomes assessment for funded activities (surveys and other instruments and means; for example incorporate electronic surveys, such as that exemplified in <http://www.zoomerang.com/survey.zgi?p=UOWPRCSCJ>).

Educational activities must address the different populations affected by CFS: pediatric, adults, men and women.

3.2 *Specific*

- Grants to patient organizations, healthcare professionals, professional societies or partnerships among them to update, develop, and run nationwide and community-based CFS-related educational programs targeted at local doctors, specialized societies, patients, and professional training programs.

Example: Lucinda Bateman, MD in Utah. Publicized through clinics and with the help of patients and patient organizations. Impact: Attendance for this CFS/FM conference in 2003: 250 patients and 150 healthcare providers. Of the 150 healthcare providers, 45 were physicians; the rest allied healthcare professionals. The next conference in May 2004 is projecting 400-500 patients/public and 200 providers from UT. Conference success is attributed to the following:

- The conference is organized by a well-respected physician with strong ties to the university;
- There is co-sponsorship between the Organization for Fatigue and Fibromyalgia Research (OFFER) and the CME provider, which is the largest private health insurance company in UT;
- There is well-organized grassroots support from the community and patients.

Example: Renee Taylor's, PhD (University of Illinois in Chicago) multidisciplinary course on fatiguing conditions and disability.

Example: Elizabeth McConn (Youth Education Committee, NJCFSA) "Our main purpose is to offer support to parents and their CFS diagnosed child or adolescent and to provide them with educational materials on pediatric CFS. Our committee is also dedicated to increasing awareness of CFS in children and disseminating reliable information to schools, pediatricians and the general public on the seriousness of chronic fatigue syndrome in young people."

- Grants for distribution of new and existing educational materials at a local and nationwide level.

Example: Physician's Manual for the Diagnosis and Treatment of Chronic Fatigue Syndrome distributed by the State of New Jersey to all its licensed physicians (see appendix 10 for comment by Dr. Kenneth Friedman).

- Grants for biannual live and/or web-based regional and national workshops or ground rounds on diagnosis, management, and treatment of CFS and other chronic fatiguing illnesses (CFS, cancer-related fatigue, autoimmune disease-related fatigue, fatiguing illness as a reflection of toxic exposures, etc).

Example: HRSA, NIH, CDC workshops and their web-based resources.

- Grants for education programs aimed at raising awareness for detection and intervention of disability among pediatric and adult CFS patients.

Example: Debra Price-Ellingstad (U.S. Department of Education's Office of Special Education and Rehabilitation Services) forwarded two policy

letters (appendices 8 and 9) as examples of how a child with CFS would be eligible for special education and related services under IDEA.

Appendix 1

List of professional societies, government agencies, individuals and patient organizations contacted in gathering of data, experiences and ideas.

Professional societies

American Medical Association (AMA)

Michael D. Maves, M.D.; Executive Vice President
515 North State Street
Chicago, Illinois 60610
Phone: 312-464-4000
Fax: 312-464-4184
E-mail: michael_maves@ama-assn.org

Association of American Medical Colleges (AAMC)

Michael E. Whitcomb, M.D.
Senior Vice President for Medical Education
2450 N Street, N.W.
Washington, D.C. 20037-1126
Phone: 202-828-0505
Fax: 202-838-1125
E-mail: whitcomb@aamc.org
Website: www.aamc.org

American Dental Association (ADA)

James B. Bramson, D.D.S
Executive Director
211 East Chicago Avenue
Chicago, Illinois 60611-2616
Phone: 312-440-2700
Fax: 312-440-7488

American Dental Education Association (ADEA)

Richard W. Valachovic, DMD, PhD, MPH; Executive Director
1625 Massachusetts Avenue, N.W., Suite 600
Washington, DC 20036-2212
Phone: 202-667-9433
Fax: 202-667-0642

American Osteopathic Association (AOA)

Douglas O. Woods, DO, PhD, President
1090 Vermont Ave. N.W., Suite 510
Washington, DC 20005
Toll-free phone: (800) 962-9008

General phone: (202) 414-0140

Fax: (202) 544-3525

American Physical Therapy Association (APTA)

Jody Gandy, PT, Ph

Director of Education

1111 N. Fairfax St. Alexandria, VA 22314

Phone : 800-999-2782 Ext. 3203

American Occupational Therapy Association (AOTA)

Janie Scott

4720 Montgomery Lane, P.O. Box 31220

Bethesda, MD 20024-1220

Phone: 301-652-2682

American Psychological Association (APA)

Brennan Harmuth

Manager of Continuing Education

750 1st St. NE

Washington, DC 20002

Phone: 202-336-5994

National Association of School Nurses (NASN)

Janis Hootman, RN, PhD, NCSN

President (nasn@nasn.org; Hoot@teleport.com)

Sue Will, RN, PHN, LSN, BS, MPH

President-Elect

Western office

1416 Park Street, Suite A

Castle Rock, CO 80109

Phone: 866-627-676; 303-663-2329; 303-663-0403

Eastern Office

163 U.S. Route #1

P.O. Box 1300

Scarborough, ME 04070-1300

Phone: 877-627-6476; 207-883-2117; 207-883-2683

American College of Physicians (ACP)

Headquarters

190 North Independence Mall West

Philadelphia, PA 19106-1572

Washington Office

2011 Pennsylvania Avenue NW, Suite 800

Washington, DC 20006-1837
Phone: 202-261-4500 or 800-338-2746

American Association of Colleges of Osteopathic Medicine (AACOM)
Per Dr. Don Weaver, Dr. Doug Wood from the AOA
is the same contact for this association.

American Academy of Family Physicians (AAFP)
P.O. Box 11210
Shawnee Mission, KS 66207-1210
Toll free: 800-274-2237
Local: 913-906-6000

American Academy of Nurse Practitioners (AANP)
Jan Towers, PhD, NP-C, CRNP, FAANP
Director of Health Policy
Office of Health Policy Contact Information
American Academy of Nurse Practitioners
Office of Health Policy
PO Box 40130
Washington, DC 20016
E-mail: dcoffice@aanp.org

American College of Rheumatology (ACR)
1800 Century Place, Suite 250
Atlanta, GA 30345-4300
Phone: 404-633-3777
Fax: 404-633-1870

American Academy of Neurology (AAN)
1080 Montreal Avenue
Saint Paul, MN 55116
Phone: 800-879-1960 or 651-695-2717
Fax: 651-695-2791
E-mail: memberservices@aan.com

American Academy of Physician Assistants (AAPA)
950 North Washington Street
Alexandria, VA 22314-1552
Phone: 703-836-2272
Fax: 703-684-1924
E-mail: aapa@aapa.org

American College of Sports Medicine (ACSM)

James R. Whitehead
Executive Vice President
PO Box 1440
Indianapolis, IN 46206
Phone: 317-637-9200 Ext. 144
E-mail: jwhitehead@acsm.org

National Association of Social Workers (NASW)

Ms. Winnie Reilly, Continuing Education
750 First Street, NE, Suite 700
Washington, DC 20002-4241

American Psychiatric Association (APA)

1000 Wilson Boulevard, Suite 1825
Arlington, VA 22209-3901
Phone: 703-907-7300
E-mail: apa@psych.org

American Speech – Language – Hearing Association

10801 Rockville Pike
Rockville, MD 20852
Phone: (Professionals/Students) 800-498-2071
Phone: (Public) 800-638-8255

American Association of Clinical Endocrinologists (AACE)

1000 Riverside Avenue, Suite 205
Jacksonville, FL 32204
Phone: 904-353-7878
Fax: 904-353-8185

American College Health Association (ACHA)

Executive Director
P.O. Box 28937
Baltimore, MD 21240-8937
410-859-1500 (Voice)
410-859-1510 (Fax)

American School Health Association (ASHA)

President
David K. Lohrmann, PhD, CHES, FASHA
Indiana University
Dept. of Applied Health Science / HPER Bldg. 116

Bloomington, IN 47405-4801
dlohrman@indiana.edu

Council on Chiropractic Education (CCE)

Martha S. O'Connor, Ph.D., Executive Vice President
8049 North 85th Way
Scottsdale, Arizona 85258-4321
Telephone: 480-443-8877
Fax: 480-483-7333
E-Mail: cce@cce-usa.org
Website: www.cce-usa.org

Acupuncturists, Somnologists, Massage therapists, Nutritionists, Physicians in student health centers.

Government agencies

U.S. Department of Education
U.S. Department of Health and Human Services
Centers for Disease Control and Prevention
Human Resources and Services Administration

Individuals and Patient Organizations

Lucinda Bateman, MD
Fatigue Consultation Clinic
1002 E South Temple (Ste 408)
Salt Lake City, UT 84102

Renee Taylor, PhD
Associate Professor
University of Illinois at Chicago
Department of Occupational Therapy
College of Applied Health Sciences
1919 West Taylor Street
Chicago, IL 60612-7250

Debra Price-Ellingstad
Department of Education's Office of Special Education and Rehabilitation Services,
telephone at 202-260-2121, e-mail at: debra.price-ellingstad@ed.gov

Kim McCleary (CFIDS Association)

Jill McLaughlin

Jon Sterling (NJCFSA)

Elizabeth McConn (Youth Education Committee, NJCFSA)

Michael Glick, DD Chairman of Diagnostic Sciences, New Jersey Dental School

Dr. Adam Perlman (Institute of Complimentary and Alternative Medicine)
perlmaad@umdnj.edu

Appendix 2

Letter sent to professional societies for gathering of data, experiences and ideas.

Dear (ORGANIZATION),

Recent studies suggest that there are 800,000 chronic fatigue syndrome (CFS) patients within the United States. More complete epidemiological studies currently being done by the Centers for Disease Control and Prevention may increase that estimate. The cost of CFS is placed in the billions of dollars secondary to lost productivity and healthcare expenses. For these reasons CFS is a national health concern.

In response to this concern, the Department of Health and Human Services has impaneled a federal advisory committee, the Chronic Fatigue Syndrome Advisory Committee (CFSAC). This advisory committee's purpose is to make recommendations to the Secretary of Health regarding appropriate actions to be taken by the Federal Government to address the CFS healthcare challenge. The CFSAC meets with representatives of the Centers for Disease Control and Prevention, the National Institutes of Health, the Social Security Administration, the Food and Drug Administration and the Human Resources and Services Administration who are involved in government programs dealing with CFS.

The Education Subcommittee of the CFSAC calls upon the (ORGANIZATION) to work with us to determine the tools and methods needed to provide effective and comprehensive medical care to patients with CFS. As part of this goal, the CFSAC has established an Education Subcommittee to assist the full committee with the development of recommendations as regards CFS-specific educational activities. To this end, the Education Subcommittee is gathering information, conducting research, and analyzing issues and facts relevant to CFS-specific educational activities. The subcommittee will also report to the CFSAC and provide recommendations for the CFSAC's deliberation.

The CFSAC Education Subcommittee requests (ORGANIZATION) assistance in gathering information on what health care organizations are doing to educate their members about CFS. Information that would be helpful includes:

- Specific information on CFS available to (ORGANIZATION) member and affiliates
- The number of articles appearing in (ORGANIZATION) literature that includes information on CFS
- The number of presentations that have included information on CFS at national meetings
- Specific data regarding recommended treatment procedures
- The reimbursement codes recommended for (professionals) to use when treating CFS patients

