

Accommodation and Compliance Series

Accommodation and Compliance Series: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

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Preface

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JAN'S Accommodation and Compliance Series

Introduction

JAN's Accommodation and Compliance Series is designed to help employers determine effective accommodations and comply with Title I of the Americans with Disabilities Act (ADA). Each publication in the series addresses a specific medical condition and provides information about the condition, ADA information, accommodation ideas, and resources for additional information.

The Accommodation and Compliance Series is a starting point in the accommodation process and may not address every situation. Accommodations should be made on a case by case basis, considering each employee's individual limitations and accommodation needs. Employers are encouraged to contact JAN to discuss specific situations in more detail.

For information on assistive technology and other accommodation ideas, visit JAN's Searchable Online Accommodation Resource (SOAR) at <u>https://AskJAN.org/soar</u>.

Information about Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

ME/CFS is a complex illness and symptoms of ME/CFS may seem similar to many other illnesses. ME/CFS requires **three** symptoms:

Not being able to participate in routine activities that were possible before becoming ill, such as work, school, social life, and/or personal life, that:

- Lasts for more than 6 months
- Is accompanied by fatigue that is:
- Often serious
- Just started (not lifelong)
- Not the result of ongoing activities
- Not from more than usual effort
- Not made better by rest

Post-exertional malaise (PEM). Worsening of symptoms after physical, mental, or emotional effort that would not have caused a problem before the illness. Symptom onset can be immediate or delayed for hours or days. This is sometimes referred to as "crashing" by people with ME/CFS.

Unrefreshing sleep. People with ME/CFS may not feel better even after a full night of sleep (e.g., feeling just as tired upon waking up as before going to bed).

In addition, **at least one** of the following symptoms is also required: **Impaired memory or ability to concentrate.** People with ME/CFS may have trouble remembering, learning new things, concentrating, or making decisions.

Orthostatic intolerance (symptoms that occur while standing or sitting upright). People with ME/CFS may feel lightheaded or dizzy when standing upright and may even faint.

OTHER COMMON SYMPTOMS:

- Muscle pain
- Pain in the joints without swelling or redness
- Headaches of a new type, pattern, or severity
- Swollen or tender lymph nodes in the neck or armpit
- A sore throat that is frequent or recurring
- Gastrointestinal symptoms
- Genitourinary symptoms
- Sensitivity to light, sound, touch, and smell
- Chills and night sweats
- Visual disturbances
- Nausea
- Allergies or sensitivities to foods, odors, chemicals, or medications

Disease onset can be either gradual or sudden, and the course can be unpredictable and varies by individual. Some individuals report that even everyday activities (e.g., grocery shopping, attending medical appointments) can worsen their symptoms. The effects of ME/CFS can be substantially limiting.

Currently, there are no medications approved specifically for the treatment of ME/CFS. However, healthcare providers can treat the symptoms and comorbid conditions. Techniques to help individuals cope with the disease can also improve their quality of life.

Managing PEM should be considered to limit symptoms. During PEM, other symptoms may get worse or first appear, including difficulty thinking, problems sleeping, sore throat, headaches, feeling dizzy, or severe fatigue. PEM can start immediately after the exertion or be delayed for hours or days. It may take days, weeks, or longer to recover from a crash. Sometimes individuals may not be able to leave their home or even get out of bed during crashes. People with PEM may not always be able to predict what will cause a crash or how long it will last. Practicing pacing strategies to minimize and

manage PEM can lead to stabilization or improvements in pain, sleep, fatigue, cognition, and other symptoms. It can also prevent worsening of these symptoms. Pacing activity may improve quality of life considerably and even increase function.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and the Americans with Disabilities Act

The ADA does not contain a definitive list of medical conditions that constitute disabilities. Instead, the ADA defines a person with a disability as someone who (1) has a physical or mental impairment that substantially limits one or more "major life activities," (2) has a record of such an impairment, or (3) is regarded as having such an impairment. For more information about how to determine whether a person has a disability under the ADA, see <u>How to Determine Whether a Person Has a Disability</u> under the Americans with Disabilities Act Amendments Act (ADAAA).

Accommodating Employees with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

People with ME/CFS may develop some of the limitations discussed below, but seldom develop all of them. Also, the degree of limitation will vary among individuals. Be aware that not all people with ME/CFS will need accommodations to perform their jobs and many others may only need a few accommodations. The following is only a sample of the possibilities available. Numerous other accommodation solutions may exist.

Questions to Consider:

- 1. What limitations is the employee experiencing?
- 2. How do these limitations affect the employee and the employee's job performance?
- 3. What specific job tasks are problematic as a result of these limitations?
- 4. What accommodations are available to reduce or eliminate these problems? Are all possible resources being used to determine possible accommodations?
- 5. Once accommodations are in place, would it be useful to meet with the employee to evaluate the effectiveness of the accommodations and to determine whether additional accommodations are needed?
- 6. Do supervisory personnel and employees need training?

Accommodation Ideas:

Limitations

Decreased Stamina/Fatigue

- Accessories for Scooters
- Aide/Assistant/Attendant
- All-Terrain Scooters
- Anti-fatigue Matting
- Elevating Wheelchairs
- Ergonomic and Pneumatic Tools
- Ergonomic Assessments
- Ergonomic Equipment
- Examination and Procedures Chair
- Flexible Schedule
- Head Support for Wheelchairs
- Job Restructuring
- Low Task Chair
- Mechanic's Seats and Creepers
- Multi-Purpose Carts
- Periodic Rest Breaks
- Scooters
- Stand-lean Stools
- Stools for Cutting Hair
- Telework, Work from Home, Working Remotely
- Walkers
- Wearable Anti-fatigue Matting
- Wheelchair Accessible Scales
- Wheelchair Mounts
- Wheelchairs
- Worksite Redesign / Modified Workspace

Dizziness

- Alerting Devices
- Alternative Lighting
- Fall Protection
- Flexible Schedule
- Modified Break Schedule
- Padded Edging
- Personal Safety and Fall Alert Devices
- Protective Eyewear
- Rollators and Rolling Walkers
- Scooters
- Telework, Work from Home, Working Remotely
- Vehicle Rear Vision System

Memory Loss

- Additional Training Time / Training Refreshers
- Apps for Memory
- Calendars and Planners
- Electronic Organizers
- Job Coaches
- Professional Organizers
- Recorded Directives, Messages, Materials
- Reminders
- Social Skill Builders
- Support Person
- Verbal Cues
- Visual Schedulers
- Written Instructions

Mental Confusion

- Electronic Organizers
- Job Coaches
- Marginal Functions

- On-site Mentoring
- PDAs, Notetakers, and Laptops
- Professional Organizers
- Reminders
- Social Skill Builders
- Supervisory Methods
- Training Modifications
- Written Instructions

Noise Sensitivity

- Alerting Devices
- Communicate Another Way
- Communication Access Technologies
- Fans
- Hearing Protection
- Noise Abatement
- Noise Canceling Earbuds
- Noise Canceling Headsets
- Real-time and Off-line Captioning Services
- Sound Absorption and Sound Proof Panels
- Worksite Redesign / Modified Workspace

Organizing/Planning/Prioritizing

- Applications (apps)
- Apps for Organization/ Time Management
- Calendars and Planners
- Color-coded Manuals, Outlines, and Maps
- Electronic Organizers
- Ergonomic Equipment
- Job Coaches
- Job Restructuring
- On-site Mentoring

- Organization Software
- Personal On-Site Paging Devices
- Professional Organizers
- Reminders
- Supervisory Methods
- Task Identification
- Task Separation
- Timers and Watches
- Visual Schedulers
- Written Instructions

Overall Body Weakness/Strength

- Adjustable and Ergonomic School Desks and Equipment
- Aide/Assistant/Attendant
- Animal Lift Tables
- Anti-fatigue Matting
- Battery Powered Lift Tables
- Compact Material Handling
- Elevating Wheelchairs
- Ergonomic and Adjustable Office Chairs
- Ergonomic Equipment
- Fall Protection
- Foldable / Transport Wheelchairs
- Forearm Support
- Grab Bars
- Hands Free Resuscitation Devices
- Independent Living Aids
- Large-Rated Scooters
- Large-Rated Wheelchairs
- Lift Tables
- Linen Carts
- Modified Break Schedule

- Multi-Purpose Carts
- Office Chairs with Brakes and Locking Casters
- Patient Lifts (General)
- Periodic Rest Breaks
- Personal Safety and Fall Alert Devices
- Personal Transportation and Mobility Products
- Pickups, Semis, and Heavy Equipment
- Power Assist for Manual Wheelchairs
- Scooters
- Stair Lifts
- Stand-lean Stools
- Stand-up Wheelchairs
- Stools for Cutting Hair
- Telework, Work from Home, Working Remotely
- Toileting Aids
- Walk-up Changing Tables
- Walkers
- Walkers with Seats
- Wearable Anti-fatigue Matting
- Wheelchairs
- Worksite Redesign / Modified Workspace

Pain

- Accessories for Scooters
- Adjustable Workstations for Industrial Settings
- Adjustable Workstations for Office Settings
- Aide/Assistant/Attendant
- All-Terrain Scooters
- Alternative Input Devices
- Alternative Keyboards
- Alternative Mice
- Anti-fatigue Matting

- Anti-vibration Gloves
- Anti-vibration Seats
- Anti-vibration Tool Wraps
- Automated Filing Systems
- Automatic Door Openers
- Cake Decorating and Baking Equipment
- Carts
- Chairs with Head Support
- Compact Material Handling
- Electronic Organizers
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Ergonomic and Adjustable Office Chairs
- Ergonomic and Pneumatic Tools
- Ergonomic Assessments
- Ergonomic Equipment
- Examination and Procedures Chair
- Fans
- Flexible Schedule
- Forearm Support
- Gooseneck and Other Telephone Holders
- Hair Scissors
- Head Support for Wheelchairs
- Headsets
- Light Switch Extension Handles
- Low Task Chair
- Mechanic's Seats and Creepers
- Modified Break Schedule
- Pickups, Semis, and Heavy Equipment
- Pipettes
- Professional Organizers

- Scooters
- Scribe/Notetaker
- Service Animal
- Speech Recognition Software
- Spring-Loaded Carts
- Stand-lean Stools
- Stools for Cutting Hair
- Strobe Lights
- Supine Workstations
- Talking Bar Code Scanner/Reader
- Talking Money Identifier
- Telescoping Cameras
- Telework, Work from Home, Working Remotely
- Van Conversion
- Wearable Anti-fatigue Matting
- Wheelchair Accessible Scales
- Wheelchair Carts/Trailers
- Wheelchair Mounts
- Wheelchairs
- Worksite Redesign / Modified Workspace
- Workstation Space Heaters
- Writing Aids

Photosensitivity

- Alternative Lighting
- Anti-Glare Filters for Fluorescent Lights
- Cubicle Doors, Shields, and Shades
- Fluorescent Light Tube Covers
- Full Spectrum or Natural Lighting Products
- LED Light Filters
- Lighting Gel Filters
- Vehicle Window Tinting and Shades

Sleeping/Stay Awake

- Apps for Sleep/ Fatigue
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Flexible Schedule
- Modified Break Schedule
- Sleep Alerting Devices
- Strobe Lights

Standing

- Accessories for Scooters
- Adjustable Drafting Tables
- Adjustable Workstations for Industrial Settings
- Adjustable Workstations for Office Settings
- All-Terrain Scooters
- Anti-fatigue Matting
- Assist Lift Cushions
- Elevating Lift and Office Chairs
- Ergonomic and Pneumatic Tools
- Examination and Procedures Chair
- Flexible Schedule
- Grab Bars
- Handheld Computers (General)
- Head Support for Wheelchairs
- Low Task Chair
- Periodic Rest Breaks
- Proper Sitting / Standing Techniques
- Scooters
- Stair Assists
- Stand Aids
- Stand-lean Stools
- Stand-up Wheelchairs

- Stools for Cutting Hair
- Van Conversion
- Wearable Anti-fatigue Matting
- Wheelchair Accessible Scales
- Wheelchair Carts/Trailers
- Wheelchair Mounts
- Wheelchairs

Stress Intolerance

- Apps for Anxiety and Stress
- Behavior Modification Techniques
- Counseling/Therapy
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Flexible Schedule
- Job Restructuring
- Marginal Functions
- Modified Break Schedule
- Supervisory Methods
- Support Animal
- Support Person

Suppressed Immune System

- Disability Awareness/Etiquette Training
- Hand Protection
- Physical/Social Distancing Signage
- Policy Modification
- Telework, Work from Home, Working Remotely
- Worksite Redesign / Modified Workspace

Temperature Sensitivity

- Air Deflectors
- Cold Resistant Gloves
- Cooling Clothing

- Fans
- Flexible Schedule
- Heated Clothing
- Heated Ergonomic and Computer Products
- Heated Gloves
- Portable Air Conditioners
- Telework, Work from Home, Working Remotely
- Vent Covers
- Workstation Space Heaters

Use of Mobility Aids

- Accessories for Scooters
- Adjustable and Ergonomic School Desks and Equipment
- Adjustable Massage Tables
- Adjustable Workstations for Industrial Settings
- Adjustable Workstations for Office Settings
- Automatic Door Openers
- Boat Access
- Door Knob Grips and Handles
- Ergonomic and Pneumatic Tools
- Evacuation Devices
- Flexible Schedule
- Height Adjustable Table Legs
- Job Coaches
- Light Switch Extension Handles
- Monitor Risers
- Pool Lifts
- Portable Ramps
- Ramps
- Spring-Loaded Carts
- Stair Lifts
- Telework, Work from Home, Working Remotely

- Threshold Ramps
- Van Conversion
- Wheelchair Accessible Lecterns
- Wheelchair Carts/Trailers
- Wheelchair Lifts
- Work Platforms

Work-Related Functions

Light

- Alternative Lighting
- Anti-Glare Filters for Fluorescent Lights
- Flexible Schedule
- Fluorescent Light Tube Covers
- Full Spectrum or Natural Lighting Products
- LED Light Filters
- LED Lighting
- Lighting Gel Filters
- Modified Lighting
- Non-Fluorescent Lighting
- Personal Visors
- Telework, Work from Home, Working Remotely
- Simulated Skylights and Windows
- Transparent Window Shades
- Vehicle Window Tinting and Shades

Move Items/People

- Adjustable Exam Tables
- Aerial Lifts
- Animal Lift Tables
- Ball Transfer Tables
- Battery Powered Lift Tables
- Cake Decorating and Baking Equipment

- Carts
- Compact Material Handling
- Compact Mobile Cranes
- Engine Lifts and Lift Plates
- Ergonomic and Pneumatic Tools
- Grab Bars Toilet Hinged Arm Support
- Hair Scissors
- Large-Rated Small Step Ladders
- Lifting Aids
- Light Switch Extension Handles
- Manhole Cover Lifts
- Multi-Purpose Carts
- Pickups, Semis, and Heavy Equipment
- Pipettes
- Pool Lifts
- Proper Lifting Techniques
- Rolling Safety Ladders
- Spring-Loaded Carts
- Stainless Steel Carts and Worktables
- Swing Away Grab Bars
- Tire Handling
- Transfer Aids
- Transfer Sheets
- Trashcans
- Vacuum Lifts
- Vacuum Pickup Tools
- Walk-up Changing Tables

Noise

- Cubicle Doors, Shields, and Shades
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines

- Fans
- Flexible Schedule
- Folding Wall Partitions and Room Dividers
- Noise Abatement
- Noise Canceling Headsets
- Strobe Lights
- Telework, Work from Home, Working Remotely

Off Site Access

- Accessible Vehicles
- Accessories for Scooters
- All-Terrain Scooters
- All-Terrain Wheelchairs
- Examination and Procedures Chair
- Flexible Schedule
- Head Support for Wheelchairs
- Low Task Chair
- Personal Transportation and Mobility Products
- Scooters
- Stair Assists
- Telework, Work from Home, Working Remotely
- Transportation Assistance
- Van Conversion
- Wheelchair Accessible Scales
- Wheelchair Carts/Trailers
- Wheelchair Mounts

Parking

- Accessible Parking Space
- Flexible Schedule
- Telework, Work from Home, Working Remotely
- Wheelchairs

Policies

- Additional Training Time / Training Refreshers
- Aide/Assistant/Attendant
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Flexible Schedule
- Marginal Functions
- Modified Break Schedule
- Periodic Rest Breaks
- Physical/Social Distancing Signage
- Policy Modification
- Reassignment
- Service Animal
- Sleep Alerting Devices
- Strobe Lights
- Supervisory Methods
- Support Animal
- Telework, Work from Home, Working Remotely
- Touchless Faucets

Stress

- Apps for Anxiety and Stress
- Behavior Modification Techniques
- Counseling/Therapy
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Flexible Schedule
- Job Coaches
- Job Restructuring
- Marginal Functions
- Modified Break Schedule
- Monitor Mirrors

- Odor Control
- On-site Mentoring
- Service Animal
- Simulated Skylights and Windows
- Strobe Lights
- Supervisory Methods
- Support Animal
- Support Person
- Telework, Work from Home, Working Remotely
- Uninterrupted Work Time

Temperature

- Air Deflectors
- Cold Resistant Gloves
- Cooling Clothing
- Fans
- Flexible Schedule
- Foot Warmers
- Heat Resistant Gloves
- Heated Clothing
- Heated Ergonomic and Computer Products
- Heated Gloves
- Telework, Work from Home, Working Remotely
- Modified Break Schedule
- Vent Covers
- Workstation Space Heaters

Use Cognitive Function

- Additional Training Time / Training Refreshers
- Aide/Assistant/Attendant
- Color Coded System
- Counting/Measuring Aids

- Electronic Dictionaries
- Electronic Organizers
- Extra Time
- Fractional, Decimal, Statistical, or Scientific Calculators
- Job Coaches
- Line Guides
- Marginal Functions
- Modified Break Schedule
- On-site Mentoring
- Personal On-Site Paging Devices
- Professional Organizers
- Reassignment
- Reminders
- Service Animal
- Social Skill Builders
- Support Person
- Training Modifications
- Uninterrupted Work Time

Work Site Access

- Accessible Toilets and Toilet Seats
- Accessories for Scooters
- Adjustable Workstations for Industrial Settings
- Adjustable Workstations for Office Settings
- All-Terrain Scooters
- Anti-fatigue Matting
- Automatic Door Openers
- Boat Access
- Braille and/or ADA Signage
- Door Knob Grips and Handles
- Examination and Procedures Chair
- Flexible Schedule

- Head Support for Wheelchairs
- High Visibility Floor Tape and Paint
- Low Task Chair
- Portable Ramps
- Ramps
- Scooters
- Service Animal
- Smart Locks/Keyless Entry Locks
- Stair Assists
- Stair Tread/Textured Tape
- Support Animal
- Telework, Work from Home, Working Remotely
- Van Conversion
- Walkers
- Wearable Anti-fatigue Matting
- Wheelchair Accessible Scales
- Wheelchair Carts/Trailers
- Wheelchair Lifts
- Wheelchair Mounts
- Wheelchairs
- Worksite Redesign / Modified Workspace

Work Station Access

- Accessories for Scooters
- Adjustable and Ergonomic School Desks and Equipment
- Adjustable Desk Top Workstations for Office Settings
- Adjustable Workstations for Industrial Settings
- All-Terrain Scooters
- Anti-fatigue Matting
- Articulating Keyboard Trays
- Assist Lift Cushions
- Automatic Door Openers

- Chair Mats
- Chairs for Little People
- Chairs for People who are Tall
- Dual Monitors
- Elevating Lift and Office Chairs
- Ergonomic and Adjustable Office Chairs
- Ergonomic Equipment
- Examination and Procedures Chair
- Expanded Keyboards
- Forearm Support
- Forward Leaning Chairs
- Head Support for Wheelchairs
- Large-Rated Chairs
- Low Task Chair
- Monitor Mirrors
- Monitor Risers
- Mousing Surfaces
- Proper Sitting / Standing Techniques
- Stair Assists
- Stand-lean Stools
- Supine Workstations
- Van Conversion
- Wheelchair Accessible Scales
- Wheelchair Carts/Trailers
- Wheelchair Mounts
- Wheelchairs
- Work Platforms
- Zero Gravity (reclining) Chairs

Situations and Solutions:

The following situations and solutions are real-life examples of accommodations that were made by JAN customers. Because accommodations are made on a case-by-case basis, these examples may not be effective for every workplace but give you an idea about the types of accommodations that are possible.

A customer service representative with chronic fatigue syndrome and memory and concentration problems had difficulty answering some customer questions.

She was accommodated with written materials to help her remember information and a private office to reduce distractions.

A teacher with chronic fatigue syndrome had difficulty meeting the physical demands of her job and was exhausted by early afternoon.

She was provided with a teacher's aid, her off-hour was moved to the afternoon, and she was excused from afternoon recess duty.

A student with chronic fatigue syndrome had difficulty keeping up with class notes.

He was accommodated with a laptop computer to use in class.

An employee with sickle cell anemia has disclosed that they are experiencing limitations due to chronic fatigue.

The individual has noticed that the quality of her work suffers near the end of their shift and is requesting accommodations to help with this. The employer agrees to modify the individual's schedule so that she has a 1-2 hour break in the middle of the shift as an accommodation so that the individual can rest before resuming the work shift. To accomplish this, the employer extends the individual's shift end-time so the individual works a normal amount of hours despite this long break.

A flight attendant with chronic fatigue syndrome was missing a lot of work due to fatigue.

Her doctor recommended that she reduce the amount of traveling she was doing. She wanted to continue working full-time so requested reassignment to an office job.

A therapist with chronic fatigue had difficulty maintaining the stamina needed to work full time

Part of the problem was that she had a difficult commute to and from work every day. She asked her employer if she could telework two times a week and do her paperwork on those days. Her employer had never had an employee telework before so decided to allow it on a trial basis to determine whether it would work. After trying it for a month, the employer agreed to allow the employee to continue teleworking.

A school psychologist with chronic fatigue syndrome was having difficulty working at full production.

She was allowed to schedule appointments in the morning, which gave her

uninterrupted time in the afternoon to complete paperwork. She was also allowed to schedule several short rest breaks throughout the day and use of sick leave as needed.

An operating-room nurse with chronic fatigue syndrome had difficulty rotating schedules.

She was accommodated with a permanent day schedule.

A design engineer with chronic fatigue syndrome had difficulty working full-time. He was allowed to work-at-home three days a week.

A daycare director with chronic fatigue syndrome had difficulty getting to work on time and maintaining a full-time schedule.

She was allowed a later start time and a part-time schedule.

A social worker with chronic fatigue syndrome experienced headaches and photosensitivity.

Accommodations included changing the lighting in her workstation from fluorescent lighting to task lighting, adding a glare guard to her computer monitor, providing window blinds, and implementing other workstation changes to enhance ergonomics.

Products

There are numerous products that can be used to accommodate people with limitations. JAN's Searchable Online Accommodation Resource at https://AskJAN.org/soar is designed to let users explore various accommodation options. Many product vendor lists are accessible through this system; however, JAN provides these lists and many more that are not available on the Web site upon request. Contact JAN directly if you have specific accommodation situations, are looking for products, need vendor information, or are seeking a referral.

Resources

Job Accommodation Network

West Virginia University PO Box 6080 Morgantown, WV 26506-6080 Toll Free: (800) 526-7234 TTY: (304) 293-7186 Fax: (304) 293-5407 jan@askjan.org https://askjan.org

The Job Accommodation Network (JAN) is a free consulting service that provides information about job accommodations, the Americans with Disabilities Act (ADA), and the employability of people with disabilities.

Office of Disability Employment Policy

200 Constitution Avenue, NW, Room S-1303 Washington, DC 20210 Toll Free: (866) 633-7365 odep@dol.gov https://www.dol.gov/agencies/odep

The Office of Disability Employment Policy (ODEP) is an agency within the U.S. Department of Labor. ODEP provides national leadership to increase employment opportunities for adults and youth with disabilities while striving to eliminate barriers to employment.

American Chronic Pain Association

P.O. Box 850 Rocklin, CA 95677-0850 Toll Free: (800) 533-3231 Fax: (916) 632-3208 <u>ACPA@theacpa.org</u> <u>http://www.theacpa.org</u> The purpose of the American Chronic Pain Association is to facilitate peer support and education for individuals with chronic pain and their families so that these individuals may live more fully in spite of their pain.

American Occupational Therapy Association 6116 Executive Boulevard, Suite 200 North Bethesda, MD 20852-4929 Direct: (301) 652-6611 members@aota.org https://www.aota.org/

The American Occupational Therapy Association (AOTA) is the national professional association established in 1917 to represent the interests and concerns of occupational therapy practitioners and students of occupational therapy and to improve the quality of occupational therapy services.

American Physical Therapy Association

http://www.moveforwardpt.com/Default.aspx

MoveForwardPT.com is the official consumer information website of the American Physical Therapy Association.

Arthritis Foundation 1330 W. Peachtree Street Suite 100 Atlanta, GA 30309 Direct: (404) 872-7100 http://www.arthritis.org

The Arthritis Foundation is committed to raising awareness and reducing the unacceptable impact of arthritis, a disease which must be taken as seriously as other chronic diseases because of its devastating consequences. The Arthritis Foundation is leading the way to conquer the nation's leading cause of disability through increased education, outreach, research, advocacy and other vital programs and services.

Bateman Horne Center of Excellence Fax: (801) 359-7404 https://batemanhornecenter.org/

Improving lives impacted by myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), post-viral syndromes, and related comorbidities through clinical care, research, and education.

Centers for Disease Control and Prevention 1600 Clifton Rd Atlanta, GA 30333 Toll Free: (800) 232-4636 https://www.cdc.gov/

The Centers for Disease Control and Prevention are dedicated to protecting the health and safety of people - at home and abroad, providing credible information to enhance health decisions, and promoting health through strong partnerships.

Genetic and Rare Diseases Information Center (GARD)

P.O. Box 8126 Gaithersburg, MD 20898-8126 Toll Free: (888) 205-2311 Fax: (301) 251-4911 https://rarediseases.info.nih.gov/

The Genetic and Rare Diseases (GARD) Information Center is a program of the National Center for Advancing Translational Sciences (NCATS) and funded by two parts of the National Institutes of Health (NIH): NCATS and the National Human Genome Research Institute (NHGRI). GARD provides the public with access to current, reliable, and easy to understand information about rare or genetic diseases in English or Spanish.

Institute for Chronic Pain PO Box 193 Stillwater, MN 55082 http://www.instituteforchronicpain.org/

The Institute for Chronic Pain is an educational and public policy think tank whose mission is to change the culture of how chronic pain is treated. We engage in research, development, and promotion of scientifically accurate information related to the field of chronic pain management. We do so by bringing together thought leaders from around the world to provide academic-quality information that is approachable to all stakeholders in the field, particularly, patients, their families, and society, more generally. The staff and fellows of the Institute are specialists in chronic pain management as well as healthcare policy and management.

International Association for CFS/ME

9650 Rockville Pike Bethesda, MD 20814 Direct: (301) 634-7701 Fax: (301) 634-7099 membership@iacfsme.org http://www.iacfsme.org

IACFS/ME is a membership organization for clinicians as well as research and health care workers professionally engaged in CFS activities.

Mayo Clinic

13400 E. Shea Blvd. Scottsdale, AZ 85259 Direct: (480) 301-8000 http://www.mayoclinic.org/

The Mayo Clinic's mission to inspire hope and contribute to health and well-being by providing the best care to every patient through integrated clinical practice, education and research.

MedlinePlus 8600 Rockville Pike Bethesda, MD 20894 <u>custserv@nlm.nih.gov</u> https://medlineplus.gov

MedlinePlus is the National Institutes of Health's Web site for patients and their families and friends. Produced by the National Library of Medicine, the world's largest medical library, it brings you information about diseases, conditions, and wellness issues in language you can understand. MedlinePlus offers reliable, up-to-date health information, anytime, anywhere, for free.

National Center for Biotechnology Information 8600 Rockville Pike Bethesda, MD 20894 pubmedcentral@ncbi.nlm.nih.gov https://www.ncbi.nlm.nih.gov/

The National Center for Biotechnology Information advances science and health by providing access to biomedical and genomic information.

National Fibromyalgia & Chronic Pain Association

3857 Birch St. Suite 312 Newport Beach, CA 92660 <u>nfa@fmaware.org</u> <u>https://www.fmaware.org/</u>

The National Fibromyalgia & Chronic Pain Association (NFMCPA) is a 501(c)3 not for profit organization. We support people with chronic pain illnesses and their families and friends by contributing to caring, professional, and community relationships. Through continuing education, networking with support groups and advocates, and affiliation with professional organizations, the members of the NFMCPA have a place to be informed, get involved, and recognize achievements.

National Organization for Rare Disorders

55 Kenosia Avenue Danbury, CT 06813-1968 Toll Free: (800) 999-6673 Direct: (203) 744-0100 Fax: (203) 263-9938 http://www.rarediseases.org

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

Office on Women's Health

Department of Health and Human Services 200 Independence Avenue, SW Room 712E Washington, DC 20201 Toll Free: (800) 994-9662 Direct: (202) 690-7650 Fax: (202) 205-2631 http://www.womenshealth.gov/

The Office on Women's Health (OWH), part of the U.S. Department of Health and Human Services (HHS), works to improve the health and sense of well-being of all U.S. women and girls. OWH serves as the focal point for women's health activities across HHS offices and agencies and leads HHS efforts to ensure that all women and girls achieve the best possible health.

Open Medicine Foundation

29302 Laro Drive Agoura Hills, CA 91301 Direct: (650) 242-8669 info@omf.ngo https://www.omf.ngo/

Open Medicine Foundation (OMF) envisions improved health care for patients suffering from multisystem chronic, complex diseases with collaboration between patients, clinicians, and researchers.

The Enviromental Illness Resource

162 Bramham Drive Oakdale Court Harrogate, North Yorkshire, England HG3 2-2UB Toll Free: (441) 423-528055 <u>support@ei-resource.org</u> http://www.ei-resource.org/

The Environmental Illness Resource seeks to provide those with environmental illnesses with information of the highest quality in the hope that this will lead to improved quality of life and perhaps even recovery of good health. In addition, to provide a free and open online community in which members may exchange information between themselves and support each other in their healing journeys.

The Myalgic Encephalomyelitis Action Network (#ME)

1217 Wilshire Blvd. Unit 3639 Santa Monica, CA 90403 info@meaction.net https://www.meaction.net/

A patient-led organization working for recognition, education, and research so that, one day, all people with ME will have support and access to compassionate and effective care.

The Solve ME/CFS Initiative

P.O. Box 36007 Los Angeles, CA 90036-0007 Direct: (704) 364-0016 <u>solvecfs@solvecfs.org</u> <u>http://solvecfs.org/</u>

The CFIDS Association of America is the nation's leading charitable organization dedicated to conquering CFIDS, also known as chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (M.E.).

U.S. ME/CFS Clinician Coalition

https://mecfscliniciancoalition.org/

The U.S. ME/CFS Clinician Coalition was formed in 2018 by a group of American ME/CFS expert clinicians who have collectively spent hundreds of years treating many thousands of ME/CFS patients. Founding members have served on the expert panel that authored the National Academy of Medicine's 2015 report on ME/CFS, have authored primers on clinical management, have contributed to the CDC's medical education initiatives, and have served on the Health and Human Services' CFS Advisory Committee before it was sunsetted in 2018. Many founding members have been and continue to be actively involved in ME/CFS research.

Workwell Foundation

P.0. Box 1435 Ripon, CA 95366 Direct: (209) 599-7194 Fax: (209) 599-4047 https://workwellfoundation.org/

Workwell Foundation exercise physiologists provide expertise to support a diagnosis, functional assessments, and treatment in the areas of ME/CFS, Fibromyalgia and other fatigue-related illnesses.

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