

Link Index

[US National Links for News & Information: CFIDS/ME](#)

[US National Links for Fibromyalgia](#)

[US Regional & Local Links](#)

[US National Health Agencies](#)

[US Regional Patient/Provider Tools](#)

[International Links & Agencies](#)

[Other relevant illnesses / co-existing conditions](#)

[Caregiver Resources](#)

[Treatment Centers for CFIDS/ME and/or FM](#)

US National Links for News & Information: CFIDS/ME

[Co-Cure - Cooperate and Communicate for a Cure](#) ~ Information Exchange

Forum for CFS and FM - search archives on keywords or subscribe for free medical and research updates.

[CAA - CFIDS Association of America](#) ~ Largest national CFIDS organization dedicated to public awareness and policy campaigns. Articles and patient and professional resources are available at their website.

[CFIDS & Fibromyalgia Self-Help](#) ~ Source for online courses, a library, and a store specifically designed for CFIDS and FM patients.

[Health Rising](#) ~ An informative blog created by Cort Johnson, in December 2012, that features frequent reviews and reports on current news and developments pertaining to CFS and FM.

[ImmuneSupport.com](#) ~ A proactive health site offering articles, community message boards and an online store for, but not limited to, CFIDS/ME and FM.

[Institute for Molecular Medicine](#) ~ Studies conducted and reviewed by Garth L. Nicolson, Ph.D. on CFIDS, Gulf War Illness and autoimmune illnesses.

[M.E./CFS Information Page](#) ~ Site featuring collection of articles and a blog compiled by prominent M.E. advocate.

[ME/CFSCommunity](#) ~ User-collaborative online community, ME-CFSCommunity is a creation of cfsKnowledgeCenter which promotes practical information, guidance and numerous resources.

[Open Medicine Foundation](#) ~ Supporting collaborative research for Neuro-Immune Disease by fundraising and patient engagement.

[Phoenix Rising](#) ~ Site with a vast amount of information about ME/CFS, with a concentrated focus on research and current issues, by way of published articles, a blog and newsletter. Phoenix Rising was founded in 2004 by Cort Johnson who has since left and created Health Rising.

[R.E.S.C.I.N.D.](#) - Repeal Existing Stereotypes about Chronic Immunological and Neurological Disease. This site, R.E.S.C.I.N.D. is no longer available, but a link is provided to another site that provides history about the conception of the May 12th International Awareness Day.

[The CFS REPORT](#) ~ Source of current news and commentary on CFIDS.

[Back to top](#)

US National Links for Fibromyalgia

[ABOUT.COM - Fibromyalgia & CFS](#) ~ Branch of a large internet info-network - news and data about FM & CFIDS reported by a journalist with FM.

[American Fibromyalgia Syndrome Association - AFSA](#) ~ Organization dedicated to funding research to advance the study of causes and treatments for FM.

[Co-Cure - Cooperate and Communicate for a Cure](#) ~ Information Exchange Forum for both CFS and FM - search archives on keywords or subscribe for free medical and research updates.

[Fibromyalgia Community](#) ~ Created in 1996 and maintained by longstanding FM advocate, Chip Davis, FMS Community offers one of the oldest email support and discussion lists FM (FIBROM-L) as well as an on-line newsletter, *FMS Community*. Sign up for either at their home page.

[Fibromyalgia Information Foundation \(FIF\)](#) ~ Started in 1995 by Dr. Robert Bennett and Sharon Clark, Ph.D., FNP, at the Oregon Health & Science University (OHSU) and foundation continues to be maintained by clinicians and researchers at OHSU.

[Fibromyalgia Network](#) ~ Organization established in 1988 with primary focus on education, which is accomplished through a comprehensive website and a quarterly journal, *Fibromyalgia Network*.

[National Fibromyalgia and Chronic Pain Association - NFMCPA](#) ~ Dedicated to building a united patient and medical community to create a strong voice and organizational base to educate and execute advocacy programs regarding access to care, scientific research, diagnosis and treatment for people suffering with chronic pain from fibromyalgia and overlapping conditions. To learn more about their programs and resources, visit their website.

[ImmuneSupport.com](#) ~ Proactive health site offering articles, community message boards and an online store for, but not limited to, FM and CFIDS/ME.

[Back to top](#)

US Regional & Local Links

CO ~ [Rocky Mountain CFIDS/FM Association](#)

CT ~ [Connecticut CFIDS & FM Association](#)

IL ~ [CFCCC](#) - Chronic Fatigue Syndrome, Fibromyalgia, & Chemical Sensitivity Coalition of Chicago

MI ~ [PANDORA org](#) - Patient Alliance for Neuroendocrine-immune Disorders Organization for Research and Advocacy

NJ ~ [New Jersey Chronic Fatigue Syndrome Association](#)

NY ~ [CF Alliance](#) (site provides link to CFAlliance Yahoo group)

VA ~ [NOVA \(Northern Virginia\) CFS/ME, FM & OI Support Group](#)

TX ~ [CFS & FM Support Group of Dallas/Fort Worth \(DFW\)](#)

[North Texas Fibromyalgia Meetup and Support Group](#)

VT ~ [The Vermont CFIDS Association](#)

WI ~ [Wisconsin ME/CFS Association](#)

[Back to top](#)

US National Health Agencies

[Centers for Disease Control and Prevention - CDC](#)

[National Institutes of Health - NIH](#)

[US National Library of Medicine ~ PUBMED](#) - Free resource consisting of millions of journal citations and abstracts. Instructions on how to search this database can be found on their home page under Using PUBMED.

[Back to top](#)

US Regional Patient / Provider Tools

[Massachusetts Rehabilitation Commission - MRC](#) ~ State organization assisting residents with disabilities to live and work independently through programs such as vocational rehabilitation, community living services, and disability eligibility determination. It also conducts annual conference with free workshops.

[Massachusetts Office of Patient Protection](#) ~ State agency assisting consumers who are enrolled in Massachusetts managed care plans and who have questions or problems.

[Massachusetts - THE RIDE](#) ~ A paratransit program run by the Massachusetts Bay Transportation Authority (MBTA) that provides door-to door transportation to people with disabilities who cannot use general public transportation. The application to request this service is available at THE RIDE website.

[Massachusetts, Voices for Health Care Consumers](#) ~ A state-specific page on Massachusetts with new materials published by Families USA, intended as a resource to assist residents with health care and related problems.

[HMO Patient Self-Defense Kit](#) ~ Information based on the book, *Making a Killing*.

[Link to lists of Health Care Providers outside of Massachusetts](#)

[Back to top](#)

International Links & Agencies

[IACFS/ME](#) - International Association for CFS/ME ~ Association of physicians and researchers who review current CFIDS/ME research and treatment literature and conduct bi-annual international scientific conferences.

AU ~ [M.E./ CFS of Australia](#) (National society with links to affiliated state organizations)

UK ~ [Action for M.E.](#)

UK ~ [The M.E. Association](#)

UK ~ [BRAME](#) (Blue Ribbon for the Awareness of M.E.)

CANADA ~ [FM-CFS - Canada](#)

CANADA ~ [National ME/FM Action Network](#)

CANADA ~ [Nightingale Research Foundation](#) (Founded in 1988 by Dr. Byron Hyde)

INTERNATIONAL ~ [World Health Organization](#)

[Back to top](#)

Other relevant illnesses/ co-existing conditions (alphabetically listed)

[Dysautonomia Information Network](#) ~ A volunteer run 501(c)(3) nonprofit organization to raise awareness of autonomic nervous system dysfunction and to promote dysautonomia education, support and networking.

[Dysautonomia International](#) ~ founded by patients, caregivers, physicians and researchers dedicated to assisting people living with various forms of dysautonomia

[Environmental Health Network - EHN](#) ~ Organization provides notices about news and events, chat groups and advocacy group with focus on environmental health.

[GulfLINK](#) ~ Official website of Force Health Protection & Readiness Policy & Programs.

[Gulf War Veteran Resource Pages](#) ~ Privately run website since 1994 (not affiliated with any government entity).

[HHV-6 Foundation](#) ~ A non-profit entity founded in 2004 concentrating on scientific exchange and clinical research on HHV-6 and its role in variety of diseases (including, but not limited to, CFIDS) and treatments appropriate for long-term use.

[Irritable Bowel Syndrome Self-Help Group](#) ~ Community for IBS sufferers, with many informative articles and other resources.

[Lyme Disease Association - LDA](#) ~ Organization dedicated to Lyme Disease education, prevention, and the raising of research funds. Various educational brochures and primers available at their website.

[Lyme Disease Foundation - LDF](#) ~ Founded in 1988, LDF is active in media outreach, education (medical and public) and research programs.

[Lyme Disease Network - LymeNET](#) ~ Comprehensive website offering online library, listing of national support groups, and a user forum.

[MCS Referral & Resources](#) ~ Organization engaged in professional outreach, patient support and public advocacy devoted to the diagnosis, treatment, accommodation, and prevention of Multiple Chemical Sensitivity disorders.

MCS - [The Canary Report](#) ~ Social networking and educational site, including a blog dedicated to Multiple Chemical Sensitivity.

[Neuro-Immune Dysfunction Syndrome - NIDS](#) ~ Articles reviewed by Dr. Michael J. Goldberg exploring the potential overlap of illnesses such as ADD/AHDH and CFIDS.

[National Sleep Foundation](#) ~ Source for information about sleep health, sleep disorders and many helpful resources.

Pain - [American Pain Foundation](#) ~ Comprehensive website for patients, families and healthcare professionals regarding pain information, awareness, programs and multiple resources.

[Back to top](#)

Caregiver Resources

[Today's Caregiver](#) ~ Leading source of information, support and guidance for family and professional caregivers. They publish *Today's Caregiver Magazine* (the first national magazine for caregivers).

[National Family Caregivers Association - NFCA](#) ~ Grassroots organization created to educate, support, empower and speak up for millions of Americans who care for chronically ill, aged or disabled loved ones.

[Well Spouse Association](#) ~ Organization dedicated to the needs of spousal caregivers which includes list of support groups for caregivers.

[Back to top](#)

Treatment Centers for CFIDS/ME and/or FM

This list provides general information about some of the leading nationally recognized treatment centers for CFIDS/ME and/or FM. Aside from the obvious (the financial investment), the choice will ultimately be yours based on what you think will meet your own needs and what you feel you can commit to after the initial visit.

What many of these centers have in common is that most of the clinicians who direct them (many of whom have also created these centers) have about twenty years of experience with these illnesses. Many of these physicians are also actively involved in research, participate in educational conferences, and/or have published research or educational medical journal articles. Therefore, this information was usually not included in the summary provided for each center.

What may vary between centers are the philosophies and research that direct treatment protocols, the types of diagnostic tests used, other programs or services offered, the amount of time to secure an appointment, the amount of time spent during consultations, how follow-up visits are handled, and fees for services. Additional details regarding these aspects and new-patient forms can be reviewed at each website.

Cost may or may not be the deciding factor. Be aware that a few centers accept certain insurance plans (including Medicare), but for the most part, patients are expected to pay for services when rendered and/or they may be required to send in a deposit or even payment in full with their registration forms. It is crucial to become fully informed about the payment and cancellation policies for any given center because some will not refund the fee. It may be possible to receive partial reimbursement from one's own insurance carrier for some of the services or tests. This will need to be pursued by the patient and here too, it is important to find out ahead of time what the coverage will be for "out-of-network" medical care. Last, but not least, the cost of travel and lodging needs to be factored in as well as follow-up care, since some centers will do this by telephone while others require that patients return to the facility. It may turn out that the difference in the total cost of going to one center versus another may not be that substantial.

FL - [Chronic Fatigue & Immune Disorders Research and Treatment Center \(aka The Chronic Fatigue Center\)](#) ~ One of the newest centers to open providing care and treatment of CFIDS and related illnesses. It was the brainchild of Dr. Nancy Klimas, who serves as Chief Medical Officer of this center located in the Miami area. Patients will undergo initial assessment of about one hour by nurse practitioners personally trained by Dr. Klimas. This data, the results from blood tests and other select diagnostic tests, and a customized treatment plan will be reviewed with patients at a follow-up appointment (also lasting about an hour). Therefore, patients will need to return to the center in about one month's time. This is a private fee-for-service clinic but lab work done at the center can be billed to patient's insurance provider.

NC - [Cheney Clinic](#) ~ The Cheney Clinic was founded in 1990 by Dr. Paul Cheney in Charlotte, NC where it operated for ten years. In 2001, the center was relocated to a medical arts building specifically designed and constructed for CFIDS patients. This practice operates with a strong focus on CFIDS and the illness processes (but clinic will see patients with other diagnoses) at the level of gene expression and its effects. Dr. Cheney describes it as a "low volume, high intensity practice with large clinical research aspect." The initial consultation will take two days to complete; therefore, it is suggested that patients arrive the day before and leave the following day. Prepayment is required when the registration forms are sent in. It is important to carefully review information regarding fees, cancellations/ rebooking and waitlist on the "policies and procedures" page at the clinic's website.

NC - [Hunter-Hopkins Center \(HCC\)](#) ~ This center was founded in 1995 by Dr. Charles Lapp. This clinic employs the Stepwise Approach - traditional medical therapy coupled with a variety of complementary therapies, including a behavioral component. This center has participated in various types of research, including FDA-approved investigational drugs which are detailed at the HCC website under "Research". New patient information (with fees and policies) can be found under HHC forms.

NY - [Fatigue Center](#) ~ A private practice which is overseen by Dr. Derek Enlander at two locations - Manhattan and Long Island, NY. Treatments focus on improving the immune system, which may include intramuscular injections, specific supplements and/or pharmaceutical products. An overview of treatments is provided at center's website.

NY - [Pain & Fatigue Study Center](#) ~ Though Dr. Benjamin Natelson is Emeritus Professor at the New Jersey Medical School, the center that he runs for treatment of severe fatigue or widespread pain, CFIDS and/or Fibromyalgia is actually located at the Beth Israel Medical Center (BIMC) in New York, NY. Dr. Natelson is involved in clinical research supported by the National Institutes of Health and by various pharmaceutical companies. Patients can expect the initial appointment to last about 90 minutes (at BIMC) and they are asked to get lab work done ahead of time through their own physician. Patients return in about one month's time to complete treatment planning - the focus of treatment is a multidisciplinary approach. Currently, Medicare is listed as the only insurance accepted by Dr. Natelson's office. Check the "New Patients" page for most current information.

MI - [Treatment Center for Chronic Fatigue Syndrome](#) ~ Dr. A. Martin Lerner's background is in Infectious Diseases, predominantly viral diseases, including virally induced heart disease. Dr. Lerner holds five patents related to improvements made in CFIDS through the use of antiviral agents. Therefore, this practice focuses on the persistent herpes virus infections that

have been found in CFIDS (i.e. Epstein-Barr Virus, Cytomegalovirus and Human Herpes Virus 6). Diagnostic work-up is reviewed on the FAQ's page at the center's website. For information about appointments and Dr. Lerner's availability, go to their "Contact Us" page. The office is located in Beverly Hills, MI.

UT - [Fatigue Consultation Clinic](#) ~ In 2000, Dr. Lucinda Bateman opened the Fatigue Consultation Clinic in Salt Lake City, Utah. The center is concerned with providing a more thoughtful evaluation process and sharing this information not only with patients, but with all involved providers. Presently, anyone interested in being seen at this clinic, is advised to call and inquire about appointment availability.

This summary is provided for your general information. Please consult with your physician or other healthcare provider in matters pertaining to your medical care. See our full [Disclaimer](#).

[Back to top](#)