

Rocky Mtn CFS News



Volume 2, Issue 2

Summer 1999

Recent Meetings

VOLUNTEERS ARE STILL NEEDED FOR NUTRITION STUDY 2!

This research tests food extracts which may be beneficial to persons with CFS. It is a collaborative project between Dr. Jim Jones of National Jewish Center and Dr. Barbara Smith of the Department of Food Science and Human Nutrition at Colorado State University. It has been approved by the National Institutes of Health (NIH) and by the Food and Drug Administration (FDA).

WHO? CFS diagnosis, ages 18-55, male and female

WHAT? Score severity of CFS symptoms daily at bedtime for eight weeks. Take five capsules/day during weeks 3-4 and 7-8 of the eight week.

WHEN? Can start immediately. Ongoing until numbers are met.

WHERE? Meet once to fill out forms, get detailed instructions, and sign informed consent form. The rest is done in your own home and by mail and telephone (and perhaps e-mail, if you have it).

CONTACTS: Barbara A. Smith (970)491-6791 or bamith@lamar.colostate.edu
Kelly Mokay (970) 495-6886 or kemokay@lamar.colostate.edu

Volunteers must be willing to avoid fish and other seafood and certain anti-inflammatory drugs (aspirin, ibuprofen, naproxen, ketoprofen)

for the eight weeks of the study. Tylenol is okay. Other medications are probably allowed and will be evaluated on an individual basis. There is no cost for the capsules.

THIS IS A CHANCE TO PARTICIPATE IN RESEARCH!

April Meeting: The April meeting topic was a discussion on local doctors. However, the meeting location was moved, unbeknownst to us until we arrived, and attendance was limited. Beth Kerkstra, the keeper of our doctors list, attended in hopes of getting updated material for the list. This did not happen, probably due to limited attendance. Not much else to report on this meeting. (Courtesy of Tim Smith)

May Meeting: Our speakers were **Jim Noel and Robert Liebross, attorneys at law.** Mr. Noel told us about the new Social Security ruling 99-2p, entitled "Titles II and XVI: Evaluating Cases involving Chronic Fatigue Syndrome" the long-awaited SSA policy statement on CFS. The ruling states that CFS, when accompanied by appropriate medical signs or laboratory findings, is a medically determinable impairment that can be the basis for a finding of disability.

The ruling quotes the CDC 1994 definition, and goes on to list examples of medical signs, including: swollen or tender lymph nodes, nonexudative pharyngitis, persistent, reproducible muscle tenderness on repeated exams with presence of tender points. Other medical signs may include anxiety, depression, short-term memory loss and

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other cognitive problems indicative of neurocognitive impairment. Laboratory findings include: elevated antibody titer to Epstein Barr virus (EBV), abnormal MRI, neurally mediated hypotension shown by tilt table or other acceptable test, abnormal neuropsychological testing results. Note that "medical signs" are simply things which your doctor notices — and writes on your chart — that are abnormal.

There will undoubtedly be dismay in the CFS medical community over the inclusion of EBV, since that virus has been ruled out as the causative agent in CFS. Nevertheless, it is included in the ruling.

Mr. Noel told us that SSA does not distinguish between physical and mental causes of disability, as do private long-term disability (LTD) insurers. SSDI does not have any time limits on mental disability benefits. LTD insurers use a 2 year time limit for mental disabilities, which policy has so far proved resistant to change.

Social Security is doing more reviews, Mr. Noel told us, and SSA expects to remove 5% of recipients from the disability rolls. Therefore, it is critical that CFS patients continue to visit their doctors regularly, every 2 - 3 months. In spite of the fact that perhaps nothing more can be done for you, these visits will help you prove you are still disabled when your case is reviewed — and it will be — by SSA.

CFS patients should keep a log of symptoms and activities. Such logs are very helpful in tracking good and bad days, and you may need the log someday to prove to SSA or to an Administrative Law Judge that you have far more bad days than good days. Logs also help at doctor visits, so you can track your progress or lack of it for your doctor. Patients should encourage their doctors to chart fully and completely, since a doctor's notation of repeated findings of tender lymph nodes, tender points, sore throat, memory and concentration problems and so on may be the only evidence you have of your continuing CFS.

Mr. Liebross spoke on LTD issues, explaining to us that private long-term disability insurance falls under ERISA law, which was originally intended to protect employee pension funds. CFS patients who have LTD insurance usually bought it while employed, or received it as part of an employee benefits package.

LTD eligibility is determined according to your insurer's policies and procedures and the terms of your individual policy. It is standard for LTD policies to promise to pay 60% of your salary if you are disabled; what most don't mention is that you must apply for and receive SSDI also. The amount that SSDI pays is then subtracted from the benefits that the LTD insurer pays you, so that while you still receive 60% of your old salary, LTD pays only a portion of that 60%.

LTD limits mental disability benefits to 2 years, in most cases. The courts have not seen fit to strike this down yet.

Some LTD companies delay awarding benefits for CFS claims. They are not allowed to change disability definitions after the policy was written, and they must tell you what claims procedures to follow. They must also notify you of their decisions and tell you how to appeal. However, the law limits damages awarded in ERISA LTD cases to actual benefits lost, so insurers may have little financial incentive to follow the letter of their policies or ERISA law.

If you are having difficulties with Social Security disability or LTD, and wish to obtain legal advice you may contact the speakers.

To contact Mr. Noel:

James Louis Noel
Attorney at Law
(303) 761-2322 1-800-671-2322

To contact Mr. Liebross:

Robert L. Liebross
Attorney and Counsellor at Law
(303) 534-5014

National News

All National News © CFIDS Association of America
Phone: 1 (800) 442-3437
PO Box 220398, Charlotte, NC 28222-0398

Research News

The **National Fibromyalgia Research Association** in Salem, Oregon, is funding a new study to determine the percentage of fibromyalgia patients who have a Chiari malformation or compression of the spinal cord. The Chiari malformation puts pressure on the brain stem and spinal cord, which can result in a variety of neurological problems such as headache in the back of the head, vision changes, NMH, muscle weakness, unsteady gait, cold, numb or tingling extremities, chronic fatigue, sleep apnea, speech impairment, gastrointestinal problems, lack of gag reflex or difficulty swallowing and an exacerbation of symptoms with exercise, including leaning the head back and coughing. Pain and fatigue alone do not indicate this condition; diagnosis is made by MRI scan and neurological testing. The treatment is neurological surgery to relieve the pressure and has resulted in alleviating symptoms for some patients. Research is still developing in this area, so don't expect your doctor to have heard about this yet.

A study published in the *European Journal of Neurology* (1999, Vol. 6, No. 1) measured **muscle contractions and recovery time** in both CFS patients and controls. Results indicated that muscle endurance was normal in CFS patients, but recovery from exertion was impaired. This was not the result of deconditioning in the CFS patients, as controls were similarly sedentary and

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did not have the impaired recovery from exertion.

Two studies looked at orthostatic intolerance (OI). *The Journal of the Autonomic Nervous System* Feb. 15, 1999 published a study done at McGill University which noted that the degree of OI correlated inversely with duration of CFS. In other words, those who had been sick longer with CFS were less likely to have OI.

A review of OI research was published in the February 1999 issue of *The American Journal of the Medical Sciences*. They note that the primary symptoms of OI - disabling fatigue, dizziness, difficulty concentrating - are often seen in CFS patients.

The New Jersey CFS Association (NJCFSA) has been monitoring the disability study underway by Dr. Benjamin Natelson's research group under contract from the Social Security Administration. There is concern that the study parameters are too narrow and could lead to a narrowing of the definition of CFS for disability determination. NJCFSA's concerns are: study is too small, geographically limited, performed by one researcher, based only on neurocognitive measures, requires patients to travel to a clinic thus limiting participation to those well enough and well off enough to travel, and includes no follow-up. NJCFSA and the CFIDS Assoc. continue to press for corrections in the methodology and are conferring with both the researcher and SSA.

Advocacy Network

The national organization also has a web site and general information email address. Contact them at

WWW: <http://www.cfids.org>

General E-mail: cfids@cfids.org

Phone: 800 442-3437

Local News

Callers Needed!

We need people to call and remind others about monthly meetings. This takes only an hour or two per month and gives you the chance to connect with other PWCs. Contact Sarah Clausen at 469-3567 for more information.

DUES for 1998:

**\$15.00 payable to
Rocky Mountain CFS Association
8865 W. Clifton Avenue
Littleton CO 80128**

Your dues help this organization to continue to provide information and services to the CFS community, including this newsletter. It costs about \$140 to copy and mail each edition of the newsletter. All work is done on a volunteer basis. **THANK YOU** to those who have paid their dues or partial dues.

The Rocky Mountain CFS Association is currently in the process of having our by-laws reviewed to assure that we remain compliant with the requirements of the State of Colorado for non-profit organizations. We will report more on this in future newsletters.

OUR CONDOLENCES and deepest sympathy to Dorothy Clingerman and to Jan Christensen who both lost their husbands earlier this year. Our thoughts and prayers are with both Jan and Dorothy.

Survey Results

Of about 220 surveys sent, we received 46 complete and 2 partial surveys returned for a 22% response rate. 41 women and 4 men returned surveys; 2 had this question missing. No one under 30 returned a survey.

Most of you (85%) attend 1 or more meetings per year. Those who don't attend often report being too sick or having other activities with family or friends. Dr. James Jones of National Jewish was the most requested speaker. Other meeting topics suggested included disability issues (we just did that one), cognitive problems and therapies, sleep disorders, CFS treatments and living with chronic illness. We will try to bring some speakers who can address some of these areas. 60% thought that the new format of speakers every other month and small group discussions would meet their needs, with 20% unsure.

A few requested meetings on weekdays or in different areas of town. However, our current meeting schedule and place already represent a compromise that most of our members find acceptable.

About half of the respondents reported being totally disabled. 60% had both CFS and Fibromyalgia. 96% reported being sick 5 years or longer.

The overwhelming majority (91%) found the newsletter interesting or helpful, with another 6% opting for sometimes interesting. Thank you for all the nice things that were said, and yes, I wish I were healthy enough to publish the newsletter more often too.

About half the respondents gave a big THANK YOU to Sarah Clausen especially, and to their callers and our other volunteers. Many thanked their callers for the wonderful job they do.

Thank You to those who responded. We

hope your responses will help us better meet everyone's needs.

Note: If you have an article, story, book review or material of general interest to our CFS community that you would like to submit for publication in the newsletter, you can send it to me email at: [redacted]@ix.netcom.com or phone me at 303 665-9014 for a street address. Submissions may be edited for content, clarity and space (if you ramble, I will edit.)

Trisha Melrose

Inspirational Thoughts

We were taught to believe that the Great Spirit sees and hears everything, and that he never forgets; that hereafter he will give every man a spirit home according to his deserts... This I believe and all my people believe the same.

Joseph (1830-1904), Nez Perce Chief

Out of the Indian approach to life there came a great freedom—an intense and absorbing love for nature; a respect for life; enriching faith in a Supreme Power; and principles of truth, honesty, generosity, equity, and brotherhood as a guide to mundane relations.

Luther Standing Bear (1868?-1939), Oglala chief

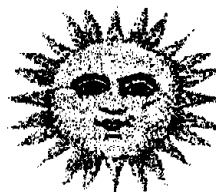


And, because it's baseball season, a few words from Yogi Berra:

I usually take a two hour nap from 1 to 4.

On traveling: It's not too far, it just seems like it is.

On baseball and life: Never give up, because it ain't over 'til it's over.



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Rocky Mountain CFS Association
d.b.a.
Rocky Mountain CFIDS/RMS
Association

Rocky Mountain CFS Assoc.
885 W. Clifton Ave.
Littleton CO 80128

Who's Who

Chairman: Sarah Clausen 303 469-3567
Secretary & Nat'l Contact Person:
 Jeannie Muench 303 973-8094
Program Chair: Sarah Clausen 303 469-3567
Program Board: Sarah Clausen, Carey Wettgen,
 Tim Smith, Janice Pelster, Rusty Dodson,
 Willow Lee
Calling Tree Chair: Sarah Clausen, Jerri Schultz
Treasurer: open
Refreshments: Carey Wettgen
Newsletter: Trisha Melrose 303 665-9014
Copying: Steve McNichol, open to volunteers
Taping: John Bliss, Jr.
Tape copies: Cindy Logan
Greeter: open
Videotaping: Rusty Dodson
Doctor List: Beth Kerkstra
Meeting Facilitator: Tim Smith

Future Meetings

We meet the third Saturday of each month
in Heitler Hall at National Jewish Hospital, Den-
ver, from 1 - 3 pm.

Meeting Schedule:

July 17 — NO meeting

August 21 — PICNIC at National Jewish

September 18 — Carl Grimes, topic: Healthy
 Habitats

October 16 — small group discussion

November 20 — Dr. Dennis Helffenstein, cogni-
 tive topics