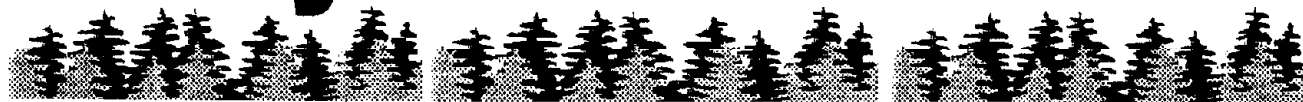


Rocky Mtn CFS News



Volume 1, Issue 4

Fall/Winter 1998

Recent Meetings

November's meeting at National Jewish Center was the first of a new series of group discussion meetings. Group members wore name tags and sat in a circle where nobody was behind anyone else. The group decided to meet in one large group rather than in smaller groups.

As a "first time" discussion, we indulged ourselves in the telling of our personal stories. Some people shared things that have been helpful to them. Participants helped to develop a list of future topics for group discussion.

The purpose of group discussion meetings will be to allow the sharing of ideas and insights derived from personal experience. Group members will share their views and wisdom. Authoritative information from experts should not be expected. Specifically, psychological experts will not be present, and participants seeking direct emotional therapy are encouraged to seek professional help elsewhere.

The approach of group discussion meetings will be to maintain a positive and encouraging attitude while focusing on controllable factors. We recognize the danger of excessive pessimism, and ask that discussion participants avoid uncontrolled expression of our common problems. Bring your questions and concerns, and we will explore useful ways to view and handle our situations.

For future group discussion meetings, we will aim toward a balanced and sustainable format as follows: 5 minutes for announcements, 10 minutes for self introductions, 15 minutes to hear

and comment about one person's story, 60 minutes to discuss the topic of the day, and 15 minutes for unrestricted discussion of recent insights and/or random items of interest. After sharing one person's story about the onset, diagnosis, progression, and management of CFS, we'll go on to a specific topic for extended discussion. Then, to nurture ongoing growth and change, we'll finish with various items of recent interest, and recently discovered insights.

Callers will announce specific topics a few days before each group discussion meeting. Potential topics for future group discussions are as follows:

- Experiences with Local Doctors
- Disability/Health Insurance Issues
- Similar/Related Illnesses
- Emotional/Psychological Coping Techniques
- Physical/Behavioral Coping Techniques
- Social/Occupational Coping Techniques
- Onset/Diagnosis/Stages of CFS
- Symptoms and Treatments
- Traditional/Alternative Medicines
- Traditional/Alternative Therapies
- Diet Supplementation/Restriction
- Information Resources and Current Research

Submitted by Tim Smith, our volunteer facilitator. Thank you, Tim!

Getting Supplements at Wholesale by Don Rudisill

The possibility of getting supplements at wholesale was discussed at the November meeting. The support group is a non-profit corporation and has a tax license. This allows us to make purchases direct from manufacture/suppliers at

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savings up to 50%. We all need to save money, thus, I propose that we start small with a limited number of products and if there is interest, slowly expand what is available. I have identified a source for low cost NADH, which several people present were taking. The product is Progressive Lab's BioEnergy Spray, a sublingual spray that is absorbed directly into the blood stream. One spray (.19 ml) provides: NADH 1.5mg, ATP 1.0mg, Glycerol Phosphate 1.5mg, other contents: glycerin, citric acid, natural flavoring, 1% sodium benzoate. It comes in a 30ml spray for \$19.98. 3 sprays a day corresponds to 10 mg in pill form (a high percentage of the NADH is destroyed in the digestive process). This is about a 50 day supply depending upon your dosage. They also sell a magnesium & malic acid product called ATP Plus where (6 tabs) contain: Magnesium Hydroxide 300 mg, Malic Acid 1200 mg, 180 tabs (30 days at 6/day) would cost \$7.50. We make no claims about these products and they should be used under the supervision of your physician. Progressive Labs makes many other products which we could also order. We will place our first order in early January. If you have an interest in either of these products or in other products, or if you have suggestions or questions, please contact Don Rudisill. Preferred contact is via email rudisill@ecentral.com. If you don't have email, you can call Don at (303) 730-1221. *Thanks to Don Rudisill for providing this information and service.*

National News

Dr. William Reeves, who oversees CFS research at the U.S. Centers for Disease Control (CDC), has come forward to state that "The \$1.2 million that CDC falsely indicated was used to support CFS research in 1996 only represents part of the misrepresentation that fiscal year. Dr. Mahy's [Dr. Reeves' superior] di-

vision appears to have used an additional \$1.4 million of monies they reported as supporting CFS research in my branch for unrelated purposes." Dr. Reeves charges that his CDC superiors "intentionally misrepresented" CFS expenditures to Congress, the Dept. of Health and Human Services and patients, specifically in response to inquiries made by or on behalf of The CFIDS Association of America. Reeves says this pattern has continued into 1998. Dr. Reeves has requested protection under the federal "Whistleblowers Protection Act" which is intended to protect federal employees who come forward with allegations of mismanagement and waste. Senator Harry Reid of Nevada has asked the General Accounting Office to investigate the CDC's research program.

Changes are proposed to ERISA, a law originally written to protect employees in employer sponsored benefit programs. The Dept. of Labor requested and got public input for revising the law, including new standards for more timely benefit determination, extended time for appeals, and improved access to information on which benefit determinations are based. The CFIDS Assoc. will have their latest response to proposed regulations on their web site.

A CFIDS name change is still under discussion, most recently at the American Assoc. for Chronic Fatigue Syndrome conference. Dr. Phillip Lee, former U.S. Assistant Secretary for Health, strongly advocated choosing a different name as many people, including physicians, do not respect the name Chronic Fatigue Syndrome. Dr. Anthony Komaroff summarized, "The name is really bad [as] it trivializes the illness, but we don't know enough to choose the right name. And we'd better damn well get it right and be prepared to live with it for the next decade."

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Internet: <http://www.cfids.org>
email: cfids@cfids.org

info in this column from the CFIDS Assoc. of America

Research News

A CDC study on CFS prevalence found that nearly 2 of every 1,000 persons has CFS and 3 - 4 of every 1,000 women have CFS. This is 50 times higher than previous CDC estimates!

Dr. Robert Suhadolnik and associates reported that up to 80% of his patients had abnormalities of the RNaseL enzyme in the 2'5'A synthetase antiviral pathway and that degree of dysregulation correlates with severity of disability. If this research result is readily duplicated and if it is unique to CFS, we may finally have a marker documenting physical evidence of our illness.

Dr. Nancy Klimas reported on her study showing low-level immune system activation in CFS patients. The level of activation of cytotoxic T-cells seems to correlate well with patient's reports of severity of illness. Other immune system studies showed higher levels of the herpes virus HHV-6 in CFS patients than in healthy controls.

Dr. David Strayer spoke about the Ampligen clinical trials, as did several patients enrolled in the trials. They reported improvements in a large number of CFS patients taking the drug. Dr. Daniel Peterson noted that good responses are only seen in selected patients. Ampligen does not yet have FDA approval and is thus available only in clinical trials. The drug is extremely expensive (\$20,000 for 40 weeks supply) and it is unclear if good results will continue for patients who stop taking Ampligen; many report relapses.

Drs. Theodore Soutzos and Ram Seth of London found that CFS patients have excessive amounts of melatonin, a sleep regulating hormone. Melatonin production was higher in patients reporting greater symptom severity.

An NIH study found the benefits of low-dose cortisone in treating CFS are outweighed by the dangerous side effect of adrenal suppression.

The above compiled from partial reports on the American Association of CFS Conference in the Nov/Dec '98 CFIDS Chronicle and the Oct. 31 CFS Electronic Newsletter.

Local News

Reminder: DUES for 1999

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

Your dues help us continue to provide information and services, including this newsletter, to PWCs in this area. Dues cover a calendar year, and are not mandatory but deeply appreciated as we are an unfunded, all volunteer PWC group. We hate to have to beg, but the treasury is very close to empty. Please give if you possibly can. Thank you.

Moving? Please let your caller or Sarah Clausen know your new address. If you don't, we can't send you a newsletter.

What happened to the Fall '98 newsletter? I had some health problems (not CFS related) over the spring and summer that resulted in major surgery at the end of September. Three weeks after surgery I got hit with a Continuing Disability Review from Social Security. I am recovering from surgery and have submitted the initial CDR and finally am able to get around to putting together this newsletter. More on the CDR process in the next newsletter, since SSA is doing more of them these days as a result of new funding from Congress.

Trisha Melrose

Writers! Want to contribute to the newsletter? Your submission should be 300 words or less, original, and of general appeal to our CFS community. It may be edited for length or clarity. You can send it to me, Trisha, via email at this address: [REDACTED]@ix.netcom.com or you can phone me (303 665-9014) for my street address.

Treatment Alternatives

At the AACFS Conference held in Boston in October, doctors discussed treating CFS patients. They generally agreed that the first treatment should focus on improving sleep. One doctor stated she tried several medications first, then ordered sleep lab testing if the medications weren't effective; her method can get HMOs to pay for testing. Several doctors saw good results with Klonopin; others said they used anti-depressants — not for depression, but for benefits in aiding sleep, treating orthostatic intolerance (neurally mediated hypotension), and possibly the immune system. The anti-depressants used were SSRIs, like Prozac or the natural remedy St. John's Wort.

For orthostatic intolerance, the doctors agreed on starting with salt and fluid loading before using fludrocortisone, a powerful drug. Elastic stockings and elevating the head of the bed were also recommended.

Some doctors reported success with narcotics for patients needing strong pain medication and noted that narcotics can lead to clearer thinking. Patients should be on low, stable doses with a preference for slow-acting Oxycontin or MS Contin.

Domestic abuse may be of concern in CFS patients when frustrated family members have difficulty dealing with a CFS sufferer who looks so good but feels so bad. [Editor's note: If you are in this position, call your local domestic violence or women's hotline for help. Check your phone book for the number of your local hotline.]

"From Fatigued to Fantastic"
a book by Jacob Teitelbaum, M.D.

Dr. Teitelbaum and his associates have done a placebo controlled double blind study on

effective treatment for Fibromyalgia (FMS) and Chronic Fatigue Syndrome (CFS). They started from the view that FMS/CFS involves hypothalamic dysfunction resulting in disordered sleep, sub-clinical hormone deficiencies (opportunistic infections and nutritional deficiencies), immune dysfunction and autonomic dysfunction (NMH). They chose 72 FMS patients, 70 of whom also met CFS criteria, with 32 patients in each group completing the study. In the treated group, 16 (50%) were much better, 13 (41%) better, with 2 patients the same and 1 much worse. In the untreated group, 3 (9%) were much better, 9 (28%) better, 11 the same, 6 worse and 3 much worse.

Treatment involved use of sleeping aids such as Elavil (5-50 mg), Flexeril (5-20 mg), Ambien (5-10mg), Benadryl (25-50 mg), Xanax (1/4-2mg), Valerian/Lemon Balm (180-360 mg/80-160mg), Melatonin 3/10 mg, Klonopin (1/2 -2mg) or Soma (1/2-1). Any of these was to be taken at bedtime. The goal was 7-8 hours of *undisturbed* sleep without waking or hangover.

Hormonal treatments used were Synthroid, Armour Thyroid, Cortef, DHEA, Florinef, Oxytocin, Natural Estrogen, Ortho-Novum, Natural Progesterone, Testosterone. Obviously the last four would depend on the patient's sex. All dosages were started extremely low and adjusted for the patient's maximum benefit.

Antiviral agents given included Valtrex (500 mg 3x day), Echinacea (300-325mg 3xday, 3 weeks per month), and Monolaurin.

Anti-Yeast treatments included a sugar elimination diet, acidophilus supplements, Nystatin or Sporanox.

If the patient has parasitic infections, Flagyl, Yodoxin, Artemesia annua, Tricyclin. Colostrum or Doxycycline were recommended.

Non-specific treatments included Nitroglycerin or Rhus Tox for muscle pain, Zoloft, Paxil, Prozac, Effexor, Serzone, Wellbutrin, St. John's Wort, Parlodel or Baclofen.

Many of the medications above are prescrip-

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tion only substances, so you will have to work with a doctor if you wish to try the full regimen. Some of them, such as Valerian, Lemon Balm, Melatonin, Echinacea, Acidopholus, and St. John's Wort, are available in health food stores.

Dr. Teitelbaum emphasizes that treatment of the symptoms must be done in an integrated manner which addresses all the underlying processes.

Dr. Paul Cheney advises patients to find the boundaries of what they can do in daily life, then stay within those boundaries. Dr. Cheney recommends anaerobic exercise (NOT aerobic), such as stretching, walking, isometrics and weightlifting with small amounts of weight. Attitudes about illness and self-worth must be adjusted. (Never confuse your net worth with your self-worth; they are independent of each other.) Accept that you are ill, but don't give up hope that you will one day be well again.

Dr. Cheney uses elimination diets to identify any food sensitivities; check with your doctor before starting such a diet.

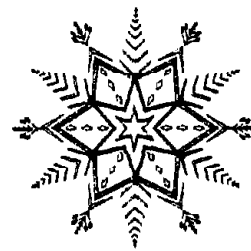
He uses magnesium, Neurotonin or Klonopin to block and regulate certain brain processes. Dr. Cheney also recommends a combination of antioxidants and bioflavonoids to reduce oxidative stress, avoiding multi-vitamins with copper and iron and making sure that magnesium and selenium are included.

Vitamins B-6 and B-12 detoxify the brain and Dr. Cheney uses megadoses of B-12 (10,000 mcg at bedtime). He also uses glutathione to help detoxify the liver, the antiviral drug Kutapressin, removal of root canal teeth, and finally, Ampligen for patients who test positive for the low molecular weight RNaseL enzyme. He cautions that while his patients on Ampligen may greatly improve, 85% relapse after the treatment is stopped.

Information in this column from *The CFIDS Chronicle* and a flyer from Dr. Teitelbaum.

Holiday Hints and Tips

- ★ Stay inside your "energy envelope". Be selective about how you use your limited energy and get plenty of rest.
- ★ Do reach out or allow people to reach out to you. Try to do at least one special, fun thing that you enjoy this holiday season.
- ★ Stay on a well-balanced, nutritious food plan, but don't take a guilt trip over an occasional indulgence in Christmas cookies or other treats.
- ★ Do one thing at a time. Make lists and try to stick to them to keep from scattering your energy on many different things at once.
- ★ Breathe to release stress. Take a deep breath through your nose, hold for 3 counts, then exhale in several sharp puffs through your mouth. Rest for 3 counts. Repeat two or three times.
- ★ If you feel blue, and lots of people do at this time of year, reach out and call someone just to talk.
- ★ Enjoy! Learn to take pleasure in simple things, like the deep blue Colorado sky on a brilliant day, the twinkle of stars or Christmas lights at night. Focus on what you have, not what you don't.
- ★ Happy Holidays to all of you!



Rocky Mountain CFS Assoc.

8865 W. Clifton Ave.
Littleton CO 80128

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

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Treasurer: Steve McNichol
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 Willow Lee, Sharon Mowery
Taping: John Bliss, Jr. tape copies: Cindy Logan
Greeter: Marge Benson
Videotaping: Rusty Dodson
Doctor List: Beth Kerkstra
Meeting Facilitator: Tim Smith
Past President: Priscilla Finnell

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:

Jan 16 - Dr. James Jones, on recent CFS re-
search.

February meeting will be a group discussion
meeting.