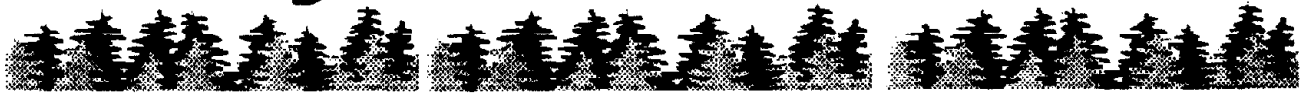


Rocky Mtn CFS News



Volume 2, Issue 1

Spring 1999

Recent Meetings

The February meeting topic was **Emotional/Psychological Coping Techniques**.

Twenty people attended the meeting, and we captured our thoughts on the white board. Those ideas are paraphrased, rearranged, and grouped below. Some ideas are opposites, and suggest that a balance of approaches might be best.

- 1 Accept and deny:** Be willing to accept changes inherent in living with CFS, perhaps by working your way through the grief process (first denial; then anger, bargaining, and depression; and finally acceptance). Yet also deny that your illness is forever, deny its power to steal your life, and maintain hope for spontaneous improvement and/or significant scientific discoveries.
- 2 Change your focus:** Give your self esteem a boost by replacing society's performance orientation with the wonders of existence. Learn "to be" instead of "to do." Live for today. Maximize the moment. Enjoy what is, not what was or what might have been.
- 3 Choose your duties:** Recognize limitations in your ability to function, and restrict your plans. Understand and rank your goals, and learn to say "no" to obligations that do not support your priorities. Plan ahead and rest as needed to prepare for important activities. Achieve steady even if slow progress toward desired tasks and important personal goals.
- 4 Stretch and learn:** Read a variety of literature to broaden your overall perspective. Participate in individual or group psychological therapy.

Gather CFS information through publications, the internet, individual discussions, or attendance at educational meetings.

- 5 Develop and reflect:** Find interests outside yourself and your condition. Explore and develop new purposes and hobbies. Find comfort and meaning in spiritual guidance, involvements, and prayer or meditation. Recognize the deeper meanings and values of life.

submitted by our meeting facilitator: Tim Smith

Dr. James Jones of National Jewish Hospital was our March speaker. Dr. Jones noted that 15 years ago doctors saw that CFS was similar to 'flu, and so suspected an infectious agent. Epstein-Barr virus, a once prime suspect, is likely not involved. He talked about the possibility of CFS stages, so that if an infectious agent is the CFS trigger, perhaps patients aren't being studied at the right time.

Dr. Jones and colleagues published a paper in August which found that CFS has elevated levels of substances called cytokines in common with allergy sufferers. Some of these are Interferon α [alpha], interleukin-6 and interleukin-10. IL-10 is thought to be the master cytokine, with low levels triggering production of the others, as happens in allergy. His findings suggest the immune regulatory system is abnormal.

His new study involves CFS and allergy patients and healthy controls. The study involves riding a stationary bike to 75% of expected exercise capacity. The overall study will last one year, with study three periods. Eligibility criteria are:

- patients must be selected by Dr. Jones.

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- age limits 16 - 45, male or female
- must not have asthma.
- CFS patients must give up anti-histamines and tricyclic antidepressants during the 2 weeks per month of the study.

Allergic subjects will exercise out of their allergy season. Patients' blood will be tested 1 hour before exercise, immediately after exercise, 6 hours and 24 hours after. The blood drawn will be examined for levels of cytokines and complements (immune proteins which help the immune system destroy bacteria). Activated complements were found in his patients, so these will be monitored as well. A symptom log will be kept after exercise sessions.

Dr. Jones commented on the Georgetown NADH study (See Research News). He said NADH is a co-enzyme associated with cellular energy transfer and is a required substance in the body. Most people get enough from a healthy diet. NADH falls under the working advice Dr. Jones gives his patients: if you want to try it and it doesn't hurt you, or put you in the poor house, doesn't prevent an underlying illness from being identified, then go ahead. It may or may not help you. Supplement results have varied greatly.

Dr. Jones repeated his hypothesis that flu-like symptoms cytokines cause — fever, aches and pains, chills, brainfog, etc. — come from a very old bodily mechanism designed to put you somewhere dark, warm and quiet so your body can heal. The irritability you get is designed to keep others away from you to prevent their getting infected. He said that unfortunately, we live in a culture and society where if you're not functioning and contributing, you're either thrown out or ridiculed. So it's very important to figure out why CFS is happening. Is it triggered by a physiological event, or a cascade of bodily reactions, or some other mechanism. Some have suggested it's a learned behavioral response, that because it's similar to depression, CFS is really just depression; Dr. Jones stressed that possibility has been dead and gone a long time. Some have not caught up with the times.

Dr. Jones discussed the importance of getting properly diagnosed. Just because you have CFS, it does not mean you cannot develop an autoimmune illness or some other medical problem. An autoimmune disease would likely meet all of the CFS physical criteria; however, if you have lupus or rheumatoid arthritis, then that is what you have and your CFS diagnosis was just an intermediate point between wellness and getting diagnosed with another identifiable disease.

Dr. Barbara A. Smith of Colorado State University spoke after Dr. Jones. She summarized the results of her nutrition study in CFS patients: calorie intake was unusually low, as was activity level; subjects made careful, nutrient packed food selections so that common nutrient levels were OK. Trace nutrients were low, but subjects took multi-vitamin and mineral supplements, although the study did not look at that intake. Patients did not gain or lose weight. Sometimes they were too tired to shop or cook and sometimes they compensated by eating fast food. Nutrition did not suffer, so her subjects must have found healthy fast food.

Dr. Smith's Nutrition Study 2 is now recruiting volunteers. It's an 8 week study with 4 phases and they hope to start this summer. Qualifications are:

- CFS patients diagnosed by CDC criteria
- age 18 - 55, male or female
- avoid eating fish or seafood for 8 weeks
- avoid anti-inflammatories (prescription, or OTC NSAIDS like aspirin, ibuprofen, naproxen) for 8 weeks of the study

The study protocol involves keeping a simple log for 2 weeks, then taking food extract capsules for 2 weeks, followed by another 2 week baseline and another set of capsules for 2 weeks. No blood test, no invasive procedures, just keep a simple log. This is your chance to participate in research!

To ask questions or to sign up for this 8 week study, contact either:

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Dr. Barbara A. Smith 790-491-6791, email:

██████████@lamar.colostate.edu

or her grad student

Kelly Mokay at 790-495-6886, email:

██████████@lamar.colostate.edu

Research News

A paper on reduced NADH (Enada®) by a group of **Georgetown University** researchers published in the *Annals of Allergy, Asthma and Immunology, Feb. 1999, Vol.82 No.2*, showed 31% (8 of 26) of patients in a double-blind, placebo controlled 4 week study responded favorably in contrast to 8% with placebo. There were no severe adverse side effects.

In a continuation of the study in which all patients knew they were taking Enada®, 72% (18 of 25) reported significant improvement with no adverse side effects. The dosage was 10 mg. (2 tablets) taken 45 minutes before breakfast.

One patient reported being overly stimulated. Dosage was not adjusted for weight or individual tolerance.

NADH, or coenzyme 1, triggers energy production through ATP generation (a component of cellular energy production) thus replenishing depleted cellular stores of ATP and improving fatigue and cognitive dysfunction. It is currently used as a treatment for Alzheimer's and Parkinson's diseases. NADH is not a cure, but may be a supportive treatment. Further research is needed.

Note: Enada® is a patented OTC substance and prices can range from \$30 - \$100 for a one month supply.

The American Journal of Medicine, the magazine of the Association of Professors of Medicine published a CFS supplement. Included

are articles on: neuroendocrinology, showing abnormalities in the hypothalamic-pituitary-adrenal (HPA) axis and autonomic nervous system; immunology, showing low NK cells and inconsistent cytokine abnormalities; neuroimaging, using PET brain scans showing significant differences between CFS, depression and healthy controls. The authors note this supports an organic cause for CFS. Interdisciplinary studies included the effect of treadmill exercise on cognitive functioning, which in CFS was significantly worse after testing than controls.

Autoimmune Technologies, a New Orleans biotech company, reports in *The Journal of Rheumatology Feb. 1999* finding a new antibody in Fibromyalgia patients. The company has licensed a blood test, Anti-Polymer Antibody (APA) Assay, which found such antibodies in 50% - 60% of diagnosed patients. These antibodies were not as frequent in patients with other autoimmune disorders. APAs were higher in patients with more severe symptoms. This shows promise of being a marker for Fibromyalgia; however more research is needed. The company is developing a commercial test kit and currently offers testing only to researchers.

Univ. of Illinois researchers may have found a gene for fibromyalgia in the HLA region dealing with immune functions. (*Journal of Rheumatology, Feb. 1999*)

London researchers say low dose (5 - 10 mg) hydrocortisone may improve CFS (*Lancet 6 Feb. 1999*). Further research must be done.

A study in the *International Journal of Molecular Medicine Feb. 1999* shows interleukin-6 levels are high in real-life CFS, but not in lab-induced fatigue. The authors suggest lab-induced fatigue may not be a good model to study immune changes in CFS; rather longitudinal studies of CFS patients may be required.

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Also in the *International Journal of Molecular Medicine* Feb. 1999, Japanese researchers published that their CFS patients showed a deficiency in DHEA-S and propose that this is associated with sleep, memory, anxiety and depression in CFS.

The CFIDS Chronicle (Jan/Feb '99) reported more on the **AACFS Conference**. Of note was a section on pediatric CFS. Dr. Bryan Carter, a child psychologist, says most psychological tests are geared toward psychiatric, not chronic physical illness, so test results are biased toward finding psychiatric illness. Also Dr. Carter notes that perhaps due to the damaging approach physicians take toward CFS, he finds families less willing to try psychological intervention for a CFS child than for a child with cancer.

In the same article, Dr. Mark Smith, a pediatrician, proposes early diagnosis in children (when they meet the CDC definition) to limit self-esteem damage, give appropriate medical treatments, and intervention to ensure kids with CFS maintain their educational and social networks.

News sources for the above include the CFS-News electronic newsletter and the CFIDS Association of America.

The CFIDS Association of America has a web site and general information email address. Contact them at:

Phone: 1 (800) 442-3437

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

General E-mail: cfids@cfids.org

The CFS-News electronic newsletter is available on the Web by subscription. For info: <http://www.cais.net/cfs-news/>

Local News

Great News! Janice Pelster's losing lottery ticket was a winner for us. Janice entered it in the Colorado Lottery's charity drawing and won \$1,000 for our group! She told us at the March meeting to collect those losing scratch game tickets, put address labels on them and the Rocky Mountain CFS Association's name, then we or she could submit them for the drawing next year. Thank you for thinking of us, Janice.

Volunteers Needed!

If you can volunteer to copy new member packets, greet people at meetings, or anything else, please do so. Contact Sarah Clausen at 303 469-3567 if you can help.

DUES for 1999:

**\$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, including this newsletter, to members of the CFS community in this area.

May 12 CFIDS Awareness Day

We currently have no plans for this due to lack of volunteers.

Supplement Club

The Supplement Club did not generate enough interest to continue. This was and still is a good idea to provide lower cost nutritional supplements for those of us who take them. However, more people must be willing to commit to make it work.

Topics of Interest

Social Security Disability Review

Social Security has announced they are planning to do 1.2 million disability reviews, called **Continuing Disability Reviews (CDR)**, this year. The CDR has the same stages as an initial application: initial CDR, reconsideration if you are denied, appeal to an Administrative Law Judge if your reconsideration is denied, appeal to the Appeals Council if the ALJ decision is not favorable, and finally, a lawsuit in federal court. Your benefits continue at least through the Reconsideration stage during a CDR. If you are initially denied, you will have to appeal (file for a reconsideration) and request that your benefits be continued.

I recently went through a CDR. It took about 5 months to complete, but the decision was favorable for me at the initial CDR stage. Here are some tips to make a review easier:

- see your CFS doctor regularly (every 2 - 3 months) and make sure s/he knows you are still unable to work, if that's the case.
- keep a daily or weekly log of your symptoms and what makes them better or worse — this helps track your symptoms for your doctor and gives you a record for your review paperwork.
- note all medicines taken and your reactions in your log
- keep in touch with someone who knows your symptoms and could do a third party statement about how your disease affects or limits your daily activities.

SSA has a procedure for frequency of reviews; if improvement is possible in your condition according to SSA, you will likely get reviewed every 3 years. Those over 50 may have an easier time. Some Persons With CFS (PWCs) over 50 have gotten a one page CDR form. Many PWCs under 50 get the 8 page

CDR form which is similar to the initial application form. If you are classified by SSA as permanently disabled, you can expect a review about every 7 years.

If you are curious about the date of your next review, call your local SSA office and ask. Have your Social Security number ready.

Above all, if you get a notice of CDR, don't panic! You *can* get through it and win the first time. I did. If the timeframe SSA allows for you to return the paperwork is ridiculously short, call and ask for an extension. Then follow up with a letter confirming your extension. Always use Certified, Return Receipt mail for anything you mail to SSA; this gives you a record. Your goal in the CDR is to put together such a good case, with so much documentation that they will have no choice but to continue your benefits.

The odds are better for you in the CDR than they were in the initial application: for CDRs, SSA must prove that you are capable of Substantial Gainful Activity — the minimum level of sedentary work. Can you sit for 2 hours at a time, 8 hours a day, and follow instructions to complete a simple task? That's sedentary work. I can't do it. Most of you probably can't either. If you get reviewed, you need to state your limitations and give examples to prove them. Your doctor, in his or her letter, must state your limitations and the medical reasons for them that would prevent you from doing sedentary work. Sarah Clausen and I both have a copy of a sample "good doctor" letter; contact either of us for a copy. That's all for now, more on this at a later date...

Trisha Melrose, your newsletter editor

Roth IRA Considerations

The taxability of Social Security Disability (SSD) income varies depending on the amount of any other taxable income (e.g., taxable LTD benefits, investment income, spousal income for

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joint returns). Depending on your level of other taxable income, either (1) current-year contributions to a Roth IRA rather than to a traditional IRA, or (2) conversion of a traditional IRA to a Roth IRA can have the effect of increasing the taxability of your SSD income, thus reducing or negating any benefit expected from use of the Roth IRA.

In all cases, SSD income is limited to no more than 85% taxable. Unless you are married filing separately (in which case your SSD income is 85% taxable regardless what you do), the amount of SSD income that is taxable depends on the level of other taxable income. Two thresholds determine how much SSD income is taxable. These thresholds are compared against the sum of (1) other taxable income and (2) one half of SSD income. For 1998, for married joint tax filers, those thresholds are \$32,000 and \$44,000, and for unmarried tax filers, those thresholds are \$25,000 and \$34,000. The amount that exceeds the higher threshold is 85% taxable, the amount that falls between the two thresholds is 50% taxable, and the amount under the lower threshold is non-taxable.

For taxpayers whose sum hovers above either threshold by no more than their total SSD income, use of a traditional IRA can have the effect of reducing the sum, thereby converting some SSD income from being more taxable to being less taxable. Reduction of the sum close to the higher threshold can reduce 85% taxable SSD to 50% taxable SSD. Reduction close to the lower threshold can reduce 50% taxable SSD to non-taxable SSD. In the best case scenario, which can occur when SSD income exceeds the difference between the thresholds (\$9000 for unmarried filers, \$12,000 for joint filers), 85% taxable SSD can actually be reduced to non-taxable SSD.

Comparatively, use of a Roth IRA rather than a tradition IRA squanders the opportunity to reduce the taxability of SSD income for certain taxpayers. For those taxpayers the chance to reduce taxable income is significant when com-

paring IRA options. If you receive SSD income and do not understand these issues yourself, more than most people you need to contact a tax advisor before using a Roth IRA.

by: Tim Smith

Not intended to replace consultation with a tax specialist. For advice on your specific financial situation, please consult a licensed tax specialist.

Internet Websites for CFS

I've been asked to do a column on Internet sites of interest to PWCs for some time now. Here is a partial list of sites I have found. Many of these sites belong to a "CFS Ring" where you may find other information and resources. I have listed the site owner or a description, then on the next line the URL or web address. Happy surfing! — *Trish*

CFIDS Association of America:
<http://www.cfids.org/>

CDC information on CFS:
<http://www.cdc.gov/ncidod/diseases/cfs/>

National Institutes of Health (NIH) homepage; includes a search engine so you can search for CFS or any other health related information. Select for the search engine when you first arrive.
<http://www.nih.gov/>

CFIDS homepage of Mary Schweitzer, a very knowledgeable PWC and current Ampligen recipient:
<http://www.cfids-me.org/>

The National CFIDS Foundation:
<http://www.cfidsfoundation.org/>

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New Jersey CFS Center (must be all on one line in your browser):

<http://www.umdnj.edu/cfsweb/CFS/home.html>

Massachusetts CFIDS organization:

<http://www.masscfids.org/>

CFS-News - an email newsletter FAQ page:

<http://www.cais.net/cfs-news/faq.htm>

American College of Rheumatology diagnostic criteria for Fibromyalgia:

<http://www.teleport.com/~nfra/Diagnos.htm>

Lists of CFIDS symptoms, from Katrina Berne, Ph.D. "Running on Empty, the Complete Guide to CFS":

<http://www.coco.com/cfids/bernesx.html>

Dr. Jay Goldstein's CFS Symptom Checklist:

<http://www.sonic.net/melissk/goldsten.html>

Help with purchasing prescription drugs for limited income patients courtesy of Bristol-Meyers Squibb company:

<http://www.phrma.org/patients/>

A medical lab's site with explanations of common medical tests: <http://dadechemistry.com/>

Good doctors list:

<http://www.co-cure.org/>

3 places to check on a doctor's credentials; go to a site and follow their directions. Note that doctors can opt for anonymity if they choose; most don't:

<http://www.ama-assn.org/aps/amahg.htm>

<http://www.certifieddoctor.org/>

<http://www.docboard.org/>

Inspirational Thoughts

The ultimate lesson all of us have to learn is unconditional love, which includes not only others but ourselves as well.

Elizabeth Kubler-Ross

Do every act of your life as if it were your last.

Marcus Aurelius, Meditations

There are three rules for dealing with those who come to us (1) kindness, (2) kindness, and (3) kindness.

Bishop Fulton J. Sheen

God, give us grace to accept with serenity the things that cannot be changed, courage to change the things which should be changed, and the wisdom to distinguish the one from the other.

Reinhold Niebuhr, The Serenity Prayer

A version of the above found on the Internet:

Lord, grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to hide the bodies of the doctors I shot when they said, "You're perfectly healthy, it's All In Your Head."

Pat J. :-)

Laughter is internal jogging and we all need our exercise.

Sidney B. Simon



Rocky Mountain CFS Assoc.

8865 W. Clifton Avenue
Littleton CO 80128

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

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: Lori Cockerhan, Willow Lee, Sharon
 Mowery
Taping: John Bliss, Jr. tape copies: Cindy Logan
Greeter: Marge Benson
Doctors List: Beth Kerkstra
Videotaping: Rusty Dodson
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:

April 17 — Group discussion: Experiences with
local doctors

May 15 — Attorney James Noel, topic: Social
Security Disability issues, including CDR.

June 19 — Video on Guaifenesin treatment

July 17 — NO Meeting

August 21 — PICNIC at National Jewish