

ROCKY MOUNTAIN CFIDS/FMS ASSOCIATION

March 2001

The Membership Has Spoken

Many thanks to members who participated in the August 2000 survey. We previously reported on the results of questions regarding meeting notification and Patient Focus Discussion groups. (See the President's Message in the December 2000 issue of this newsletter.) In addition to those questions, members also responded with comments on a variety of topics, including speakers, discussion topics and attendance, as well as general impressions of our meetings.

Several members commented that they have difficulty attending meetings due to transportation issues. Some have trouble with driving and directions, others are unable to attend due to depleted energy and other illness issues. Of those who have attended, many made helpful suggestions on improving the format and focus of our meetings.

Many suggestions were made for the use of our Lottery award. Some felt the money would best be used to help fund research, others favored keeping the funds in an endowment for ongoing operating expenses and increased services. Two members suggested using the money to help individuals specifically, which, while an honorable idea, appears to be out of the scope of our Purpose in the Articles of Incorporation. Promoting public awareness of CFS and paying professionals for appearances were also mentioned.

Many thanks to members who participated in the survey. Your suggestions for speakers and discussion topics, and your many insightful observations, will help us as we continue to grow and change as a community of support.



AACFS Conference

In January, the American Association for Chronic Fatigue Syndrome held its 5th biannual conference in Seattle. Nearly 130 presentations were made by doctors and notable CFS researchers from around the world.

A pre-conference symposium reviewed the case definition of CFS, and discussed ways in which it could be optimized. Two days of oral and poster presentations followed, covering a vast array of topics surrounding CFS, and a forum was conducted to discuss the possibility of a name change.

Among those attending were Anthony Komaroff, David Bell, Nancy Klimas, William Reeves of the CDC, as well as many other doctors, clinicians and patient advocates. Paul Cheney was unable to attend due to illness, but his paper on the possibility of circulating plasma RNAs as a biological marker for CFS was presented on his behalf.

Other presentation topics included:

- Epidemiology
- Physiology
- Microbiology
- Brain/Neurological Studies
- Immunology
- Genetics
- International Perspectives
- Prevalence
- Psychological Issues
- CFS in Children and Adolescents
- Treatment Options

For more information on the conference, see the AACFS website at: www.aacfs.org



From the President...

We've been looking for a way to help our members get to know others in the same part of the Denver metro area. Some of you will remember that our support group used to have smaller groups that met in various parts of town, but they fizzled out several years ago.

We are introducing a carpooling idea called **Ride Share**. Many thanks to our callers and substitute callers who all agreed to be Ride Share Coordinators. Coordinators will receive phone calls from people in our group who need a ride to our meetings, and from people who can offer to drive others to our meetings. Coordinators will then share names and phone numbers of drivers with riders. Drivers and riders are then expected to contact each other and make ride sharing arrangements. Please note that we cannot guarantee that enough drivers will be available for all who may want a ride.

Listed at right are Ride Share Coordinators, along with major cross streets near their homes. If you need a ride to our meetings, or can offer a ride to others, please call the coordinator nearest to you. Hopefully, the coordinator can get riders and drivers connected. You then can make your own arrangements. If you live in between two coordinators, you might call both with your offer of or request for a ride. If your area does not have a coordinator, and you would be willing to be a coordinator, please contact **Karen Reese** at (303) 377-1536.

- Tim Smith

Ride Share Coordinators

Arvada

Roberta Robertson
Wadsworth & 62nd
(303) 424-2361

Aurora

Donna Chaney
Alameda & Havana
(303) 366-6385

Dorothy Clingerman
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Boulder

Gail Souther
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Westminster

Alice Vigil
Sheridan & 92nd
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Wheatridge

Bernice Taylor
Wadsworth & 38th
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Denver

Yetti Gruenler
Hampton & Monaco
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Steve McNichols
Bellevue & Yosemite
(720) 529-5763

Bonnie Sheppard
Hampton & Sheridan
(303) 986-7465

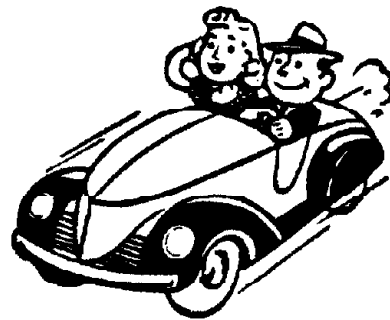
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Wadsworth & Chatfield
(303) 973-1261

Rochelle Winograd
Santa Fe & Mineral
(303) 730-3833

Kitty Sherback
Kipling & Bowles
(303) 972-1143



Meeting News

November's meeting of the Rocky Mountain CFIDS/FMS Association was a discussion meeting. The topic for the day was "Physical/Behavioral Coping Techniques." About twenty people attended the meeting, and we captured our thoughts on the white board. Here are some of the ideas we discussed:

- **Adjust Attitudes:** find things to be thankful for, let go of perfectionism;
- **Conserve Energy:** rest to prepare for a planned event; avoid draining activities;
- **Reduce Physical Stress:** look for opportunities to sit; let someone else drive;
- **Task Management:** prioritize tasks; reorder priorities; stop at half of what you think you can do.
- **Interaction with Others:** request help; delegate chores when possible; find people who understand your limitations;
- **Discover and Adapt:** discover and avoid allergens; accommodate the weather in your plans;
- **Miscellaneous Therapies:** laughter; silence; restrict external stimuli; meditate;
- **Improve coping skills:** use a journal to note helpful techniques; find additional therapies through research.

We previously discussed "Emotional/ Psychological Coping Techniques." A related future topic for a group discussion meeting will be "Social/Occupational Coping Techniques." Please join us when you are able.

*(Please see related story on page 6:
"Opportunities Found in Illness")*

*"Right now my life is just one learning experience after another. By the end of the week I should be a genius."
- Jeanette Osias*

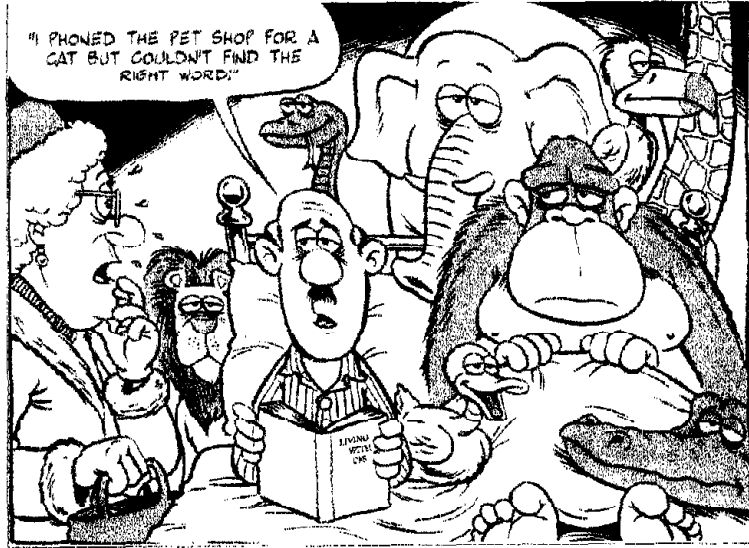
In **January**, Dr. James Jones, noted CFS researcher from National Jewish Center, spoke to our group. Dr. Jones visits with our group, at least annually, to update us on the latest research and discussion among CFS experts. At the time he spoke, he was preparing to attend the American Association for Chronic Fatigue Syndrome (AACFS) Conference in Seattle, Washington. *(See front page for more on the conference.)* Dr. Jones explained that the conference would address fatigue measurement and "chronic un-wellness" issues, noting that researchers are beginning to wonder if fatigue is really the right symptom to be measuring. He added that less than half of patients asked listed fatigue as their most bothersome complaint. Dr. Jones referred to a "potpourri of treatment issues" being reviewed, including the use of twin studies to look for predisposing gene patterns, such topics as RNASE-L pathways, cognitive function, pain sensitivity and sleep issues. He emphasized the complexity of Chronic Fatigue Syndrome, adding, "It's naïve to think it's a single bug."

Many of our members and others who go to National Jewish Center have many kinds of allergies and chemical sensitivities. Therefore, National Jewish Center does not allow smoking or fragrances such as perfumes, colognes, after-shave lotions, or any other scented products. Please do not wear any scented products to our meetings. If you do, you may be asked to leave. Thank you for your cooperation.

**Funerals Unattended:
The Necessity of Mourning Who We
Used to Be**

by Anne-Marie Vidal

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Doctors may not say exactly what they mean...



The following quotes were taken from actual medical records dictated by physicians. They appeared in a column written by Richard Lederer, Ph.D., for the Journal of Court Reporting.

Patient has chest pain if she lies on her left side for over a year.

On the second day the knee was better and on the third day it had completely disappeared.

The patient has been depressed ever since she began seeing me in 1983.

Patient has left his white blood cells at another hospital.

She slipped on the ice and apparently her legs went in separate directions in early December.

The patient left the hospital feeling much better except for her original complaints.

Easy Three-Step Dinner

(CFS/FMS user-friendly recipe)

4 to 6 boneless chicken breasts
1 bag frozen vegetable mix of your choice
2 cups 2% milk
2 cups uncooked regular rice
2 cans reduced fat cream of chicken soup
Seasoned salt, Black pepper, Paprika

1. Preheat oven to 350 degrees F.
2. Combine milk, rice, soup, salt and pepper to taste and vegetables, pour into lightly greased 13 X 9 inch baking dish. Add chicken, sprinkle with paprika.
3. Cover tightly with aluminum foil, bake in preheated oven for 90 min., stirring twice. Uncover and bake for another 15 or 20 minutes, to brown. Serves 4 - 6.

Opportunities Found in Illness

Presented by Leah A. Barrett, MS, MSW, at a one-day symposium entitled: The Spirituality/Healing Connection: Expanding Horizons in Medicine. (9/8/00, sponsored by Hematology/Oncology Associates and Poudre Valley Hospital, Fort Collins, Colorado)

- Reflect on what is really important in life; rethink your priorities.
- Find peace in "today", not waiting for the achievement of some goal.
- Appreciate the small things - the outdoors, your family, your pets, music.
- Accept difficulties in life as learning experiences.
- Let go of control - you don't have it anyway; go with the flow.
- Increase intimacy and authenticity in relationships; at home and with friends.
- Learn/observe your strengths - recognize how strong you are.
- Honor your body - let go of anger at your body and your illness.
- Look for opportunities to grow from your illness.
- Think of at least one thing you are grateful for each day.
- Do something each day to feel alive within yourself.



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This newsletter is a publication of The Rocky Mountain CFIDS/FMS Association, Inc., a 501(c)(3) public charity. It is intended to provide helpful information about CFS, FMS and related topics. The Association does not endorse any product, service or medical hypothesis, does not dispense medical advice, and assumes no liability for treatment undertaken by readers of this newsletter. For medical advice, consult your doctor.

Change of address? Need to contact the Association? Please use this handy form

Name _____ Dues/Donation \$ _____
(Voluntary Annual Dues of \$15.00 are appreciated.)

Address _____

Phone Number _____

E-Mail Address _____

Meeting Notification Preference: E-mail Voice Messaging Phone Call
(Note: Voice Messaging and Phone Calls are for local, non-toll calling area only.)

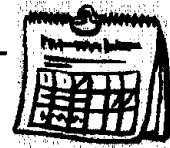
Do you have CFS? _____ How long? _____

Do you have FMS? _____ How long? _____

Comments: _____

Please detach and send to: Rocky Mountain CFIDS/FMS Association, c/o Janice Pelster,
(make checks payable to:) 3161 W. Bails Place, Denver, CO 80219-4612

Meeting Schedule



April 21, 2000 **Video of Lecture by Dr. Paul Cheney (Part 2)**
"The Pathophysiology, Diagnosis and Treatment of CFS"

*Dr. Cheney addressed the Dallas/Ft. Worth CFS Support Group in May of 1999. Group discussion will follow.
(Part 1 of the video was presented at our February meeting.)*

May 19, 2000 **Lecture Meeting: Attorney James Noel**

*Disability Attorney Noel will update us on Social Security Disability and Long Term Disability issues.
(His last update to us was in May of 1999.)*

June 16, 2000 **Video of Lecture by Dr. Myra Preston**
"Cognitive Dysfunction in CFS, and its Treatment"

A neurophysiologist, Dr. Preston discussed EEG brain wave mapping and neurofeedback therapy for cognitive dysfunction at the Dallas/Ft. Worth Support Group meeting in April of 2000. Group discussion will follow.

July 21, 2000 **No meeting - Enjoy your summer!**

Ideas? Speaker/Discussion Topics you'd like to hear? Other concerns? Let us know!
(Use the handy response form on the back of this page.)

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