

ROCKY MOUNTAIN CFIDS/FMS ASSOCIATION

c/o Janice Pelster, Treasurer
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Date: August 1, 2000
From: Tim Smith, President
[REDACTED]@compuserve.com
303-758-2496 (noon - 9 pm please)

SUMMARY

This is the first mailing from the Rocky Mountain CFS Association since the Fall of 1999. This letter includes local association news, an updated healthcare provider list, a survey (which includes a ballot for election of Directors), and a form for recommending providers for the healthcare provider list. A stamped self-addressed envelope is provided for return of the survey, and for your healthcare provider recommendations if you have any.

So that we may be sure of your continued interest in the group, **you must return the enclosed survey by August 30 to remain on the mailing and calling lists.** A ballot for election of Directors is included on the first page of the survey. **Your ballot must be postmarked by August 30 for your votes to be counted.** If you miss that deadline, you still can return the survey later to reactivate your listing.

STATE OF THE ASSOCIATION

As detailed below, several key leaders have retired. As you know, a newsletter has not been sent for almost a year. We need more volunteers to come forward to help with the operation of the support group. This is why we are taking the extraordinary step of requiring written surveys to be returned for you to remain on the mailing and calling lists. We must obtain an accurate reading of continuing interest in the support group as we make decisions regarding the group's future.

Two important aspects of the support group hang in the balance: (1) continuance of regular lecture meetings, and (2) resumption of regular newsletters. **We urgently need members willing to serve on a Speaker Committee** responsible for scheduling speakers for lecture meetings. And while we may be able to afford to pay someone to *format* a newsletter, **but we need members willing to submit articles for the newsletter.** If people don't come forward for these functions, they may not be continued.

LOTTERY AWARD!

Thanks to all who collected and submitted non-winning scratch lottery tickets with the name of our association as the charity. But particularly, thanks to the efforts of Sarah and Dave Clausen (for collecting a winning ticket), Janice and Ray Pelster (for submitting the winning ticket on Sarah's behalf), and Tim Smith (for choosing and scratching the winning amount), **the Rocky Mountain CFIDS/FMS Association has received \$10,000** of lottery winnings in the Colorado Lottery's recent 11th Annual "Everybody Wins Charity Drawing."

The award represents many years worth of our usual revenue. The association may choose to keep the funds as an endowment to provide yearly income, or we might redistribute some or all of the funds to causes such as (1) the national support group, The CFIDS Association of America, (2) CFS research, perhaps at National Jewish Center, or (3) funding for Dr. Jones take part in a conference where he otherwise would not participate.

ELECTION OF DIRECTORS

On page one of the enclosed survey, you are asked to elect a board of directors. The existence of a properly elected board of directors is important in general for administering the group, but specifically for establishing authority to make decisions regarding the lottery funds.

Since we were awarded the largest amount in this year's charity drawing, we can expect more outside scrutiny than ever before. Also, lottery officials may come around before next year's drawing asking what we've done with the proceeds. We want to have good answers supported by the decisions of a properly elected board of directors.

RETIREMENT NEWS

Three members of our leadership team retired from active involvement during the last year. **Many thanks to Jeannie Muench, Trisha Mel-**

rose, and Sarah Clausen for their many years of service to our support group. Sarah and Jeannie co-led the association for several years, while Trisha's newsletters provided a vital communication link to the association.

Two members of our support team also retired: **Bunny Cole** who had been a caller, and **John Bliss** who helped with audio taping of meetings. Thanks to **Bunny and John** for their service to the association.

Jeannie Muench retired in the Fall of 1999. Jeannie did a bit of everything over the years, including at various times being Co-President, Vice-President, Secretary, Treasurer, Librarian, Newsletter Editor and Writer, copier of articles and new member packets, CFIDS Support Network contact person, and the contact person for The CFIDS Association of America. In response to Jeannie's retirement, **Don McKinstry** became the contact person for The CFIDS Association of America, **Janice Pelster** became the Treasurer, and **Tim Smith** became the Vice President and CFIDS Support Network contact person.

Early this year, newsletter editor **Trisha Melrose** retired. Trisha provided a fine newsletter for the association, not only doing the editing, but actually writing most of the newsletter articles herself. Unless someone as willing and capable comes forward, we now need several people to replace her. **If you have computer publishing or word processing skills, please consider becoming our newsletter editor.** If you can write summary articles about our lecture meetings and/or national CFS-related news, please consider becoming a newsletter contributor. This is a critical need for the association.

Most Recently, **Sarah Clausen** retired in June. Sarah was Co-President or President for many years, headed the calling tree and efforts to schedule speakers for lecture meetings, and handled calls referred from National Jewish Center and newsletter copying/ mailing. Upon Sarah's retirement, **Tim Smith** became President, and **Karen Reese** became Secretary and will be head of the calling tree. **We need volunteers to line up speakers for lecture meetings.** Please consider helping with this important function of the group.

SPECIAL THANKS

- to **Carey Wettjen** who faithfully provides refreshments each meeting, and **Sandy Rocca** who buys one or two food trays each meeting.
- to our current telephone callers, many of whom have been callers for many years: **Ann Boyer, Jan Christensen, Dorothy Clingerman, Janet Hess, Cindy Logan, Don McKinstry, Steve McNichols, Rebecca Nicol, Roberta Robertson, Bonnie Sheppard, Katherine Sherman, Lynn Smith, Gail Souther, Alice Vigil, Rochelle Winograd, and Alice Wycoff.**
- to **Rusty Dodson, Stan Frahm, and Willow Lee** who handled the May meeting in the absence of all our regular leaders, including Willow's scheduling and assisting with setup for the day's speaker.
- to the **Knights of Columbus chapter #4796** for their recent \$300 donation.

ALTERNATE NAME

You may have noticed that an alternate "trade name" has been established for the Rocky Mountain CFS Association, Inc., and appears at the top of this newsletter. Either name may be used independently for the combined name "**Rocky Mountain CFS Association, Inc., dba Rocky Mountain CFIDS/FMS Association**" (where dba stands for "doing business as"). CFS was changed to CFIDS (Chronic Fatigue and Immune Dysfunction Syndrome) to more closely align our support group with the national support group, The CFIDS Association of America, Inc. FMS was added since many of our members also have the illness Fibromyalgia Syndrome (FMS), which is argued by some to be the same illness as CFS or CFIDS.

NON-PROFIT STATUS

The association is in good standing with federal and state authorities as a 501(c)(3) publicly supported charity. This means that your donations and voluntary dues are tax-deductible. **We ask for voluntary annual dues of \$15** (or whatever you can afford) to pay for group expenses such as newsletter production and postage, copying of handouts for meetings, and other operational expenses.

FUTURE MEETINGS (Fall, 2000)

Meetings are held on from 1 to 3 pm on the third Saturday of each month (except July and December) in Heitler Hall at National Jewish Center, 1400 Jackson Street (southwest corner of Colfax Avenue and Colorado Boulevard in Denver).

AUGUST 19: **Annual Picnic:** find us at the outside covered patio behind Heitler Hall at National Jewish Center. Meats (chicken, ham, turkey, and meatloaf), drinks, and eating utensils, plates, cups, and napkins will be provided. Please bring a potluck dish: appetizer, salad, vegetable, dessert, or whatever!

SEPTEMBER 16: **Patient Focus Discussion Meeting:** Short video from the 3/10/00 "20/20" episode regarding **Chiari Malformation** and/or **Cervical Spinal Stenosis** as possible causes of CFS and/or FMS. Special guest **Kathryn Castleberry** of Boulder will share her experience following surgery to correct cervical spinal stenosis.

OCTOBER 21: **Lecture Meeting: Dr. James F. Jones** of National Jewish Center and a nationally known CFS expert will provide his yearly update on CFS research, and any other notable CFS related news.

NOVEMBER 18: **Topical Group Discussion Meeting: Physical/Behavioral Coping Techniques**

DECEMBER 16: **No Meeting: Happy Holidays!**

RECENT MEETINGS

OCTOBER 1999: **Topical Group Discussion Meeting: Nutrition and CFS.** Attendance was small due to a one-day snow storm. **Dr. Barbara Smith**, of the Department of Food Science and Human Nutrition at Colorado State University, expected to attend but was prevented by the snow. But later she sent a page of ideas entitled "Quick and Easy Meals". Find it later in this newsletter.

NOVEMBER 1999: **Lecture Meeting: Dr. James Jones**, a nationally known CFS expert from National Jewish Center in Denver, reviewed the history and possible causes of CFS, and his current research. The following is a brief summary:

CFS has been around a long time, called "Little Fever" around 1500, "Neurasthenia" in the 1800's, referred to by symptoms of headache, tension, and fatigue in the 1900's, labeled Chronic Epstein-Barr Virus in the 1980's, and arriving at its current United States based definition in 1994. Then autonomic nervous system related symptoms brought in immune system considerations.

As for potential theories of causation, Dr. Jones indicated that infection, inflammation, and/or allergy can all be mediators leading to ongoing illness symptoms, and the potential role of altered perceptions and/or psychological factors. He suggested that many combinations of physical and psychological factors can conspire to produce CFS.

Dr. Jones was continuing his research on the effects of exercise and allergy on CFS patients.

JANUARY 2000: **Lecture Meeting: Dr. Jai Gottlieb**, a holistic medical doctor from Boulder, suggested supplementing and/or replacing the many external interventions we try with introspective-based interventions. He advocated moving beyond various physical therapies and/or oral supplements, whether over-the-counter or prescription.

Consider the inseparable mind-body unit which constantly struggles to maintain equilibrium on many fronts in our constantly changing environment. Seek balance, and perhaps balance will enable more healing and happiness. Avoid self- and society-imposed pressures to *do more, have more, and be more.*

Instead, begin with an acute awareness of your situation, and develop a clear intention for improvements you desire. Learn the techniques of deep relaxation, such as meditation. Embrace the discomfort which can result when introspection leads to greater awareness of the difference between your goal and your situation. Find the path to healing on the road of internal realities rather than in the cage of external demands.

FEBRUARY 2000: Topical Group Discussion Meeting: featured the 10/24/99 **CNN video segment** about Chronic Fatiguc Syndrome, and the 1/4/00 **Dateline video segment** about Fibromyalgia.

MARCH 2000: Lecture Meeting: **Dr. Dennis Helffenstein**, a clinical psychologist and rehabilitation Counselor from Colorado Neuropsychological Associates in Denver, reviewed neuro-cognitive problems associated with CFS and discussed techniques for enhancing communication when cognitive problems are a factor.

Problems reported by CFS patients, many of which can be tested objectively, include attention and concentration, short term memory, mental processing speed, decreased reasoning, language comprehension, word finding, visual/spatial problems, and problems with math. Short term memory, language comprehension, and math problems seem to be associated with the temporal lobes of the brain, with the remainder of the above listed problems associated with the frontal lobes.

Neuropsychological testing on CFS patients often detects deficits with attention and concentration including multitasking, short term memory more related to learning than retention, word finding, and speed of motor, auditory, and visual processing. Fatigue does not cause cognitive problems, but does exacerbate them. MRI, SPECT, and PET studies all are able to show abnormalities of structure, blood flow, and energy use respectively. Among various studies however, abnormalities in patients with CFS seem to occur in different parts of the brain with little consistency of location or intensity.

Cognitive problems can cause communication problems which can cause relationship problems. Strategies for enhancing communication include (1) monitoring and defending the ability to maintain attention and concentration, (2) avoiding interruptions when listening by writing down fleeting thoughts after indicating a need to pause briefly, (3) avoiding unwarranted conclusions due to results which may have been caused by cognitive problems, (4) assisting with topic transitions, (5) using alternative words when words are hard to

find, or receiving words from your partner, and (6) being patient with each other.

For more extensive details, a set of two audio tape recordings is available for this meeting.

APRIL 2000: Topical Group Discussion Meeting: **Disability Issues** were discussed by those present.

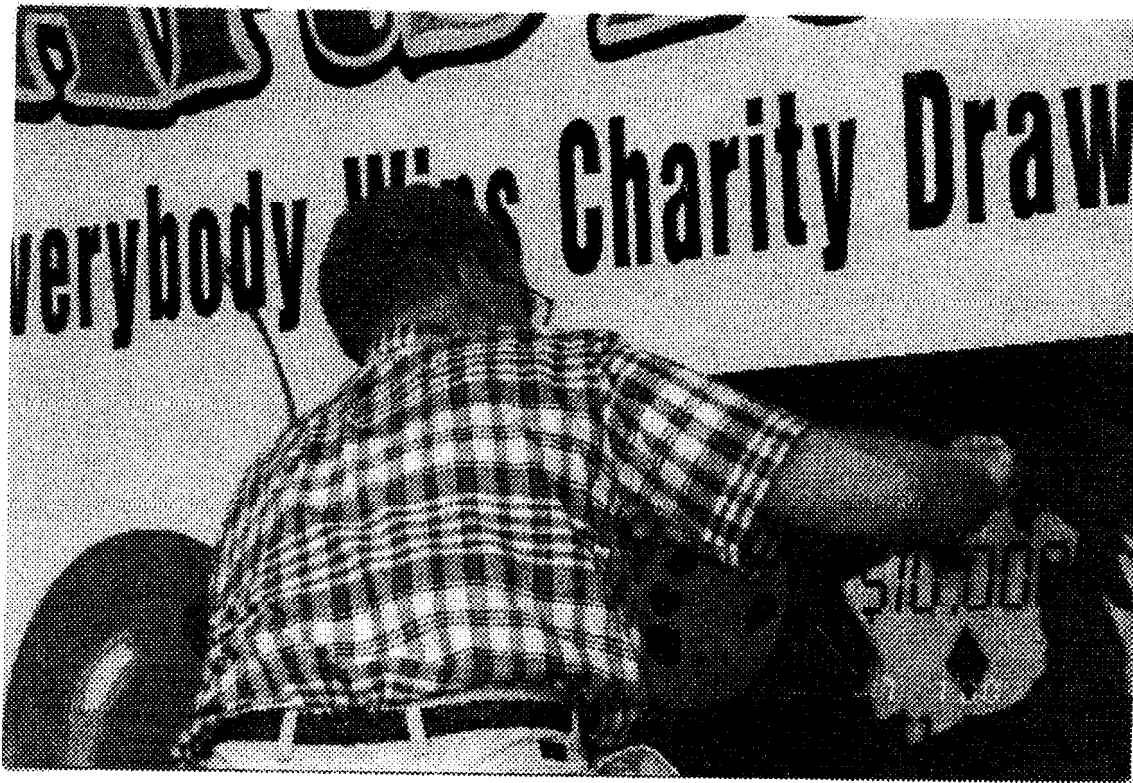
MAY 2000: Lecture Meeting: **Dr. Terry Grossman**, a medical doctor from Lakewood who specializes in alternative medicine, covered an alternative theory of causation of CFS and a variety of treatment approaches, all or many of which must be pursued simultaneously. Dr. Grossman feels CFS is a new "disease of civilization" brought on by over use of antibiotics in society, not just by people directly, but by food producers whose antibiotics ultimately become consumed by the human population. The rationale for this theory is that in human beings energy-producing ATP is made by mitochondria, bacteria responsible for converting food into usable energy, and that overuse of antibiotics defeats this process by killing the mitochondria.

Avenues of treatment include (1) restricting overgrowth of yeast, largely by restricting sugar intake, (2) identifying and handling food allergies, (3) supplementing the thyroid if needed, (4) reducing demands of stress on adrenal glands, (5) supplementing sex hormones if needed, (6) identifying and treating sugar disease if present, (7) reducing gut toxicity if problematic, (8) eliminating ingested external contaminants from heavy metals, food additives, air pollution, indoor synthetic materials, and ultraviolet radiation due to ozone depletion. Specific treatments include bouncing on mini-trampolines to increase lymph flow, intravenous "Myer's Cocktail" therapy, and use of a hyperbaric oxygen chamber.

For more details, an audio tape is available.

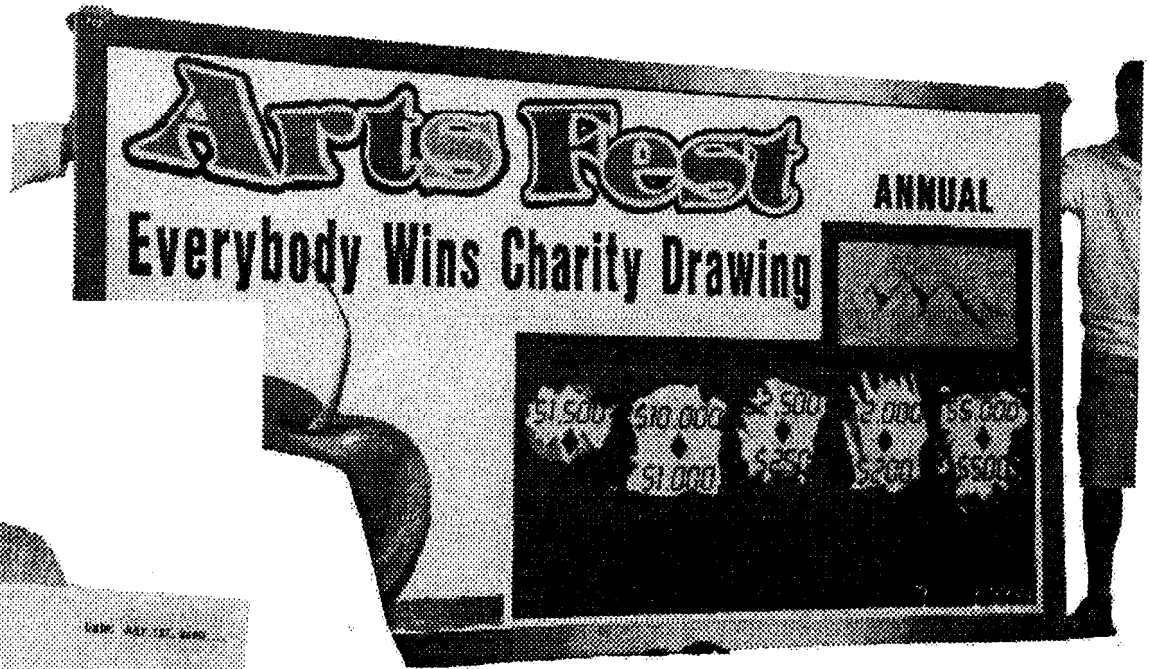
JUNE 2000: Group Discussion Meeting: turned into a **support group planning meeting** following Sarah Clausen's retirement.

JULY 2000: No Meeting: Hope you enjoyed a summer vacation!



Tim Smith,
President,
chooses and
scratches the
\$10,000.

July 1, 2000



Janice Pelster, Treasurer,
displays the award check.

Disclaimer: The Rocky Mountain CFIDS/FMS Association does not dispense medical advice or endorse any product, service, or medical hypothesis, and assumes no responsibility for treatment undertaken by readers of this newsletter.

QUICK and EASY MEALS

prepared by: Dr. Barbara Smith,
Department of Food Science and Human Nutrition
Colorado State University

Breakfast: Instant Breakfast drink (cheaper and tastier than Ensure)

Proteins: Eggs, cheese, milk, yogurt, canned chicken or water-packed tuna. Keep several boiled eggs in the refrigerator. They will keep for a few days.

Microwave a potato and top it with canned chili.

Ready-to-eat cereal with milk and fruit. Skip vitamin supplement if you choose "Total" products.

Keep on hand powdered milk, dried fruit, and egg substitute for when you do not feel like shopping. Keep extra bread in freezer or keep crackers on hand.

Canned foods are easier to prepare than fresh or frozen.

Corn, sweet potatoes, and lima beans can double as a serving of carbohydrate and a vegetable.

"Cup of Soup" or ready-to-eat canned soups

On a good day, prepare enough food to last several meals. Refrigerate or freeze the leftovers for more difficult days (e.g., small roast).

Easy soup: Canned tomatoes with equal volume water, bouillon granules, canned vegetables, canned kidney beans or chicken. Season to taste.

Instant rice

Freeze peeled banana halves on popsicle sticks. Freeze grapes or berries, peach or melon chunks (single layer spread out so they will not stick together). (When frozen, repackage.)

"Complete" pancake mix, muffin or cake mixes

Hamburger Helper, Tuna Helper

Canned or "microwavable" spaghetti, ravioli, macaroni, or other entrees.

Luncheon meats (preferably reduced fat)

A package of mixed vegetables will give you variety with one simple preparation!

To combat weight gain,

1. Choose fruit for dessert.
2. Beware of hidden fats in "fast" food.
3. Beware of "highly palatable" foods treats only in small quantities or as individual items.
4. Be aware of proximity to kitchen and boredom!
5. Distract yourself (from food) with other pleasures you can enjoy (e.g. surfing the computer, reading, knitting, letter writing, talking on the phone).