

ROCKY MOUNTAIN CFIDS/FMS ASSOCIATION

June 2001

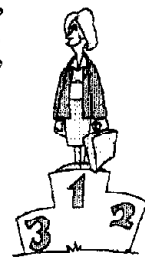
Association Secretary Wins Award



turned in the winning ticket received 10% of what we received, an additional \$1,000!

Our own **Janice Pelster**, Secretary for the Rocky Mountain CFS/FMS Association, has won the CFIDS Support Network's ACTION Award. The award recognizes individuals who educate and help others cope with CFS. Janice won in the Local Group Volunteer (PWC) category for her fundraising efforts. She's been with our Denver area support group for over 10 years. Early on, she helped raise several thousand dollars in donations. Her continued enthusiasm for fund raising paid off big in 2000. She encouraged several group members to collect and turn in non-winning scratch lottery tickets. Janice and her husband, Ray, made stickers for each of about 500 submitted tickets, listing the name of the person who turned in the ticket, and the name of our organization as the charity. One of those tickets was picked as one of five finalists. As you probably know by now, we had the chance to present our group at a public event, and scratch a giant lottery ticket to determine our final award, which was the tidy sum of \$10,000, the largest award this year from the Colorado Lottery's charity program! And since Janice and Ray gave credit to people who turned in the tickets, the person who

The award has enabled us to give back to those who have helped us. When asked what motivated her to begin fundraising, Janice explained, "Way back when, the group needed money to keep going. My husband, Ray, belonged to the Knights of Columbus, and some of their members' wives had CFS and Fibromyalgia too. I had felt so alone with this illness, and **Priscilla Finnell** and others helped me so much. I got my husband's group interested in helping us and I've just continued from there."



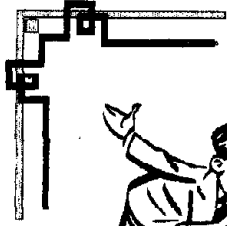
The inscription on Janice's award reads: "We cannot change yesterday. We can only make the most of today, and look with hope toward tomorrow." Thanks, Janice.

Save Those Non-Winning Scratch Tickets!

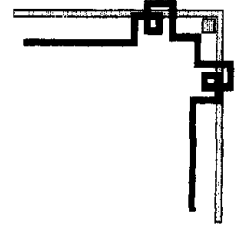
Just write your name and phone number on the back and submit them to Janice Pelster (303-936-5040). Janice will turn in the tickets to the lottery drawing, indicating our group as the charity, and your name and phone number as the submitter. Individuals get 10% of whatever the group wins! This year five charity finalists will scratch tickets June 30th at the Greeley Stampede.

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President's Corner...



June 2001 marks the end of my first year leading our Association. A big thank you to **Nadine Goranson** for continuing the tradition of providing a high quality newsletter, and to all other volunteers who help our group run smoothly.

The year started with a bang as we received \$10,000 from the Colorado Lottery Charity Drawing. **Sarah and Dave Clausen** submitted the winning ticket to our Association and received an additional 10% for their efforts. **Janice and Ray Pelster** finalized and submitted the entries to the lottery drawing. Congratulations to **Janice Pelster** for receiving the *Local Group Volunteer (PWC) CSN Action Award* for her fundraising efforts. She is listed in the Spring 2001 *CFIDS Chronicle* (a publication of the CFIDS Association of America). (See related story on page one.)

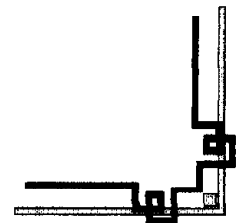
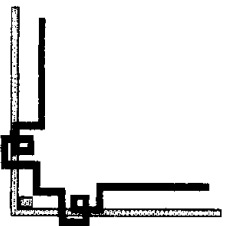
Finances: The Association donated a laptop computer to the CFS Research Lab at National Jewish Medical and Research Center, and kept the remaining lottery funds as an endowment for operating expenses. When the extraordinary effect of the lottery award is factored out, year 2000 income from dues and other donations was about \$1,200, and expenses exceeded income by about \$100. Thank you for continuing your voluntary dues and donations. They help us provide services to you and to people who cannot afford the help we offer.

RideShare: If any of you need a ride to our meetings or will offer to drive others to our meetings, please call the *RideShare* Coordinator near you as listed in the March Newsletter. If you are not paired with a driver or rider, or you don't have the March list, call **Karen Reese**, or Association Secretary.

Resource List: We need your help compiling a list of community resources (e.g., medical, housing, transportation) for people with chronic illness and associated problems. If you know of useful programs or services, please call **Karen Reese** at 303-377-1536 with the information.

Thank you for your help and participation,

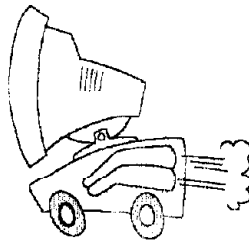
Tim



Giving Back

Our gift of \$2,000 to the CFS Research Lab at National Jewish Medical and Research Center to purchase a laptop computer is truly appreciated. Dr. James Jones' research assistant, Bristol Sorensen, wrote a Thank You letter to our President, Tim Smith. The letter read, in part:

"I was thinking how much I appreciate having this laptop computer that enables me to get my work done no matter the time or the place.



"I have been able to accomplish a tremendous amount of work over the past 4 months with the help of this laptop. First of all, Dr. Jones and myself collaborated with two other researchers on a 3-year NIH grant, which we submitted March 1, 2001. Secondly, I was asked to give a lecture at the University of Colorado at Boulder on the mind-body connection and about exercise and immunology. Thirdly, I am just finishing a comprehensive review paper regarding all of the fascinating observations that we have seen in CFS patients at NJC over the past 15 years. Lastly, I received a

Scholars Award to present the CFS research being done at NJC at the PsychoNeuroImmunology Conference in the Netherlands in May.

This laptop has been absolutely invaluable to me and the work that I am so passionately pursuing regarding Chronic Fatigue Syndrome... This laptop has been the only reason that I have been able to accomplish what I have over the past four months. I hope that you feel your money was well spent. I think that with all the amazing projects that Dr. Jones and myself have been working hard on, that we shall surely see our efforts pay off."

HELP WANTED

We need volunteers to invite, confirm, remind, host, and thank our lecture meeting speakers. If you are interested in helping the Association in this capacity, please contact Tim Smith, (303) 758-2496 or timjaysmith@att.net

Meeting News

At the May meeting we heard from Attorney James Noel, an Englewood attorney who handles disability cases. In an article published in the CFIDS Chronicle, Mr. Noel highlights tips for winning disability or Social Security claims. He writes,

- ◆ "Honesty and accuracy in reporting symptoms to your medical sources are essential.
- ◆ Use medically accepted diagnostic criteria based on the 1994 Centers for Disease Control case definition for CFS.
- ◆ Keep a log describing your symptoms.
- ◆ Obtain a pharmacy history from your pharmacy.
- ◆ Establish your own medical file organized by provider.
- ◆ See your physician as often as possible.
- ◆ File Social Security claims as soon as it is clear you cannot sustain "gainful" employment."

Mr. Noel fielded a variety of questions at our meeting. For more information, contact Attorney James Noel at: 3333 South Bannock, Ste. 888 Englewood, Colorado 80110 303-756-2322

"One of the most adventurous things left us is to go to bed. For no one can lay a hand on our dreams." - E.V. Lucas



BOOKSHELF

Faces of CFS

reviewed by Jean Harrison

David S. Bell, M.D. has written and published a new book: *Faces of CFS*.

Dr. Bell writes that he hopes this volume will: “teach a dangerously complacent public about this complex and important disease.”

More than any other book this reviewer has read about the illness, this volume can do just that. For those who would like to educate their families and friends, this highly readable book gives clear and convincing testimony. Even the most skeptical would have a difficult time doubting the veracity of Dr. Bell’s concrete observations or the validity of his clinical experience.

Instead of writing a scientific treatise, Bell has chosen to illustrate, through case histories, the defining principles of the illness, along with its variations and complications. The case histories are recalled in a warm and refreshingly unpretentious style, sometimes amusing, sometimes terribly poignant.

Seemingly effortlessly, Dr. Bell exposes falsehoods perpetuated

by the medical and psychiatric professions about CFS. For example, when he talks of patients who were self diagnosed—the portrait he paints is at odds with that which the medical establishment (and the media) would like to have us see. Dr. Bell makes it clear that people are self diagnosed due to the failure of their doctors to diagnose them; not that the ill somehow wish upon themselves symptoms they happen to read about.

“In the course of his reading journey, Gary came upon an article that described CFS. The stories of the patients in this article resonated with his own experience of the disease: sudden onset; a long, chronic course, exhaustion, headaches, pain; sensitivity to light; night sweats, the sensation—if not the reality—of high fever. He was stunned when he read that patients with CFS are exquisitely sensitive to many drugs, including anti-depressants such as the one he had taken. He felt as if he was reading his own biography. In fact, he was so persuaded that the long-standing mystery of the last year was resolved, he felt incredulous that his doctor had missed the obvious signs, which now seemed so obvious. There was just one small detail of the disease, as CFS was described in the article, that didn’t seem to fit: Gary had never really thought of himself as a yuppie.”

The same perception and sensitivity is used in the descriptions of the other patients, their struggles with the disease and its

baggage. Though some of the cases described are composites, none reads as false or improbable. The cover is a statement itself. It is a deep gray with faces, half lit, as if coming through a fog. The faces are of children, men and women, cut off rather sharply at the neck. For those of us suffering with CFS, the symbolism is clear.

The case histories are interspersed with Dr. Bell’s ruminations about human nature, his chosen lifestyle, and his views on the state of Medicine. At times, the writing is downright lyrical:

“I quickly learned that Edwin Maxwell was the man who owned the beautiful farm on the Sitwell road. I had admired this farm every time I passed it on my way to the nearby hospital. The old barns were always maintained with care. I had come to expect an orderly procession of snowdrops, tulips and lilies on tended patches of lawn every spring and summer. I could see that a lovely stream ran through the rear of the property, which looked like a European forest—tidy, but natural, as wonderfully wild as anything could be and still be called a farm...I also knew that whoever tended this farm had a certain mysterious wisdom.”

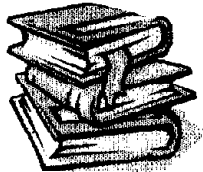
In unflinching confirmation that CFS is a physiological disease of subtlety and complexity, the book will comfort those who are newly diagnosed and those going through the inevitable periodic bouts of self-doubt. In a rather stunning passage, the doc-

tor states his conviction that: "CFS will do to medicine what quantum mechanics has done to physics. The laws once considered inviolable are turned upon their head. Just as we were comfortable with the simplistic notions of physics before relativity, doctors are comfortable with the simple notions of medicine now. It really makes little difference that these notions are inaccurate, except to those who are not helped by modern medicine."

I cannot imagine anyone who has CFS, who is an advocate for CFS, who is a caregiver for someone with CFS, not finding this book to be essential. It's the book we've all been waiting for. Most can, and probably will read it in a single sitting—it's hard to put down—thus it is the perfect book to give to those who need to understand the illness better. Those of us who live the illness will read this

book again and again. *Faces of CFS* (104 pages, paperback) is available by sending check or money order for \$25.00 to:

D.S. Bell, M.D.
P.O. Box 335
Lyndonville, NY 14098



Special thanks to Jean Harrison of Salem, Massachusetts for contributing this book review. Before becoming totally disabled with CFS, Jean worked as an oil painting conservator. Currently, she spends time with her three English toy spaniels, and works on various projects to promote awareness of the debilitating effects of CFS.

State Rebate Program

The State of Colorado offers tax, rent and heating bill rebates to low income disabled people. If you qualify, you may receive a rebate based on your income and expenses for the year 2000. Applicants must meet five requirements, including age or disability status, income limitations, residency status, dependency status and payment of property tax, rent or heat expenses. For more information, and to obtain an application form, go to:

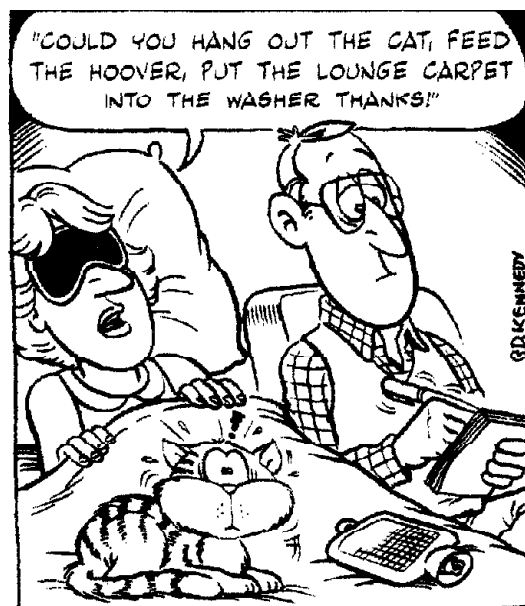
www.revenue.state.co.us

Click on "Income Tax forms and Information". On the next screen, scroll down to form **104PTC: 2000 Colorado Property Tax/Rent/Heat Rebate**. Or, call the Department of Revenue: (303) 232-2414 and ask for Form 104PTC and instructions.

Just for fun...

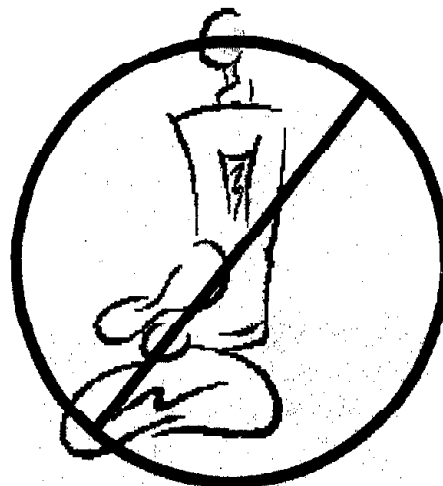
"One of the advantages of being disorderly is that one is constantly making exciting discoveries."

- A.A. Milne
Creator of Winnie-the-Pooh

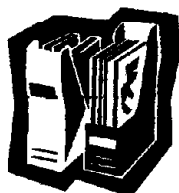


Many of our members and others who go to National Jewish Center have many kinds of allergies and chemical sensitivities. Therefore, National Jewish Center does not allow smoking or fragrances such as perfumes, colognes, after-shave lotions, or any other scented products. Please do not wear any scented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

-The Board



Media Watch



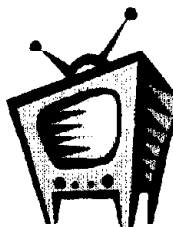
The May 21, 2001 edition of *US Weekly Magazine* carries a letter to the editor ("The Mail," p. 5) from the Executive Director of the National CFIDS Foundation, commenting on the story about Laura Hillenbrand and her best selling novel, *Seabiscuit*. (In her interview, Ms. Hillenbrand shared details of her 14-year struggle with CFS.) The letter reads, in part:

"Hillenbrand aptly conveys the severity and nature of this ailment, which is way beyond simple fatigue, as the name implies."

To read the complete interview with Laura Hillenbrand, see the May 14, 2001 issue of *US Weekly* magazine, p. 48, "Beating the Odds," by Phoebe Hoban.

The June issue of *Redbook* includes a mention of CFIDS in the article, "Adult Diseases That Threaten Your Kid." The CFIDS Association of America worked with author Denise Poretto to present a realistic, sympathetic picture of the illness. The article, which features quotes from Dr. David Bell, describes symptoms, gives information on diagnosis, and recommends supporting young people with CFIDS emotionally as well as physically.

A story about actress A.J. Langer (of *My So-Called Life* and *Three Sisters* fame) in the March 19, 2001 issue of *US Weekly* magazine, details her fight to continue working while living with Fibromyalgia. The article (p. 48), by Oliver Jones, is entitled, "A.J. Langer's Life of Pleasure and Pain."



Fibromyalgia Class

The Arthritis Foundation in Denver presents **Fibromyalgia: Regaining and Maintaining Mobility**, on Tuesday, July 10, 2001, from 6:30 - 8:30 p.m. Robert Hays, M.D., will discuss the medical aspects of staying active with Fibromyalgia. He will share information on medications, pain and sleep management, and will be joined by physical therapist, Susie Demander, who will provide tips on improving sleeping postures, stretching, flexibility and more. The class will meet at 2280 S. Albion Street, Denver, and is free and open to the public. Refreshments will be served and parking is free. Reservations are encouraged. Call: (303) 756-8622 and refer to Registration # P77-PG10.

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 _____

City _____ Phone Number _____

State _____ Zip Code _____ E-Mail Address _____

Meeting Notification Preference: (Circle one)

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**

ASSOCIATION INFORMATION

LEADERSHIP TEAM

Tim Smith.....President
[redacted]@att.net (303) 758-2496

Karen Reese.....Secretary
[redacted]@qwest.net (303) 377-1536

Janice Pelster.....Treasurer
[redacted]@qwest.net (303) 936-5040

Nadine Goranson.....Newsletter Editor
[redacted]@qwest.net (303) 678-0531

Don McKinstry.....Nat'l Contact Person
[redacted]@juno.com

Carey Wettjen.....Refreshments

BOARD MEMBERS

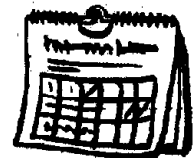
Sarah Clausen Janet Hess Jeannie Muench
Janice Pelster Karen Reese Kitty Sherback
Tim Smith

This newsletter is a publication of The Rocky Mountain CFIDS/FMS Association, Inc., a 501(c)(3) publicly supported charity. It is intended to provide helpful information about CFS, FMS and related topics. Contact us by e-mail at CFSdenver@att.net or FMSdenver@att.net. 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.

Rocky Mountain CFIDS/FMS Association
c/o Janice Pelster, Treasurer
3161 West Bails Place
Denver, CO 80219-4612

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

Meeting Schedule



July 21, 2001: No Meeting—Have a good summer!

August 18, 2001: Annual Picnic

Find us at the outside covered patio behind Heitler Hall at National Jewish Center. Meats (chicken, ham, turkey and meatloaf), drinks, eating utensils, plates, cups and napkins will be provided. Please bring an appetizer, salad, vegetable or dessert to share.

September 15, 2001: Group Discussion Meeting: CFIDS vs. Fibromyalgia-Same or Different?

This will be an opportunity to discuss similarities and differences before our Oct. lecture.

October 20, 2001: Lecture Meeting: An Integrative Approach to Fibromyalgia

Dr. Milt Hammerly is a family practitioner MD who combines traditional and alternative therapies to individualized treatment programs.

November 17, 2001: Video Lecture Meeting: Dr. Myra Preston, Neurophysiologist

Dr. Preston discusses EEG brain wave mapping and neuro-feedback therapy for cognitive dysfunction. This lecture was taped at the Dallas/Ft. Worth Support Group meeting in April 2000.

***Meetings are held at National Jewish Medical and Research Center at
1400 Jackson Street in Denver (near Colfax Ave. and Colorado Blvd.), from 1 p.m. to 3 p.m.***