

ROCKY MOUNTAIN CFIDS/FMS ASSOCIATION

Spring 2002

CFS Research Results at NJC

February's meeting featured **Bristol Sorensen**, a research assistant to Dr. James F. Jones of National Jewish Medical and Research Center (NJC). After relating her personal history with CFS illness, Bristol reported major results of a three year research study recently completed at NJC.

History: In 1994, following school in Utah on a ski scholarship, Bristol became ill but felt she couldn't really be sick since she was an athlete and a busy student. In the 18 months prior to becoming ill, she had many surgeries due to skiing accidents, had her sternum broken in a car accident (yet went rock climbing in France anyway), and finally had sinus reconstruction surgery.

Unlike previous surgeries, she didn't recover. She saw multiple doctors, and was told her illness was all in her head. She became bed-ridden, sleeping 16 hours a day. After seven months she improved, but did not get well. In 1996, she had a relapse and was hospitalized just after



starting graduate school in Colorado.

Dr. Jones diagnosed Bristol with CFS. As both an exercise physiology student and a CFS patient, she began collaborating with Dr. Jones. They developed a study involving exercise tolerance of CFS patients. In 1998, she recovered spontaneously — with no idea how. Insomnia is her only lingering symptom. After obtaining her M.S. degree in 1999, Bristol is now working toward a Ph.D.

Study: Assumptions were as follows: The cause of CFS is not known. CFS is a variable disease, waxing and waning in severity from day to day. Most CFS patients report worsening of symptoms after exercise.

Bristol and Dr. Jones hypothesized that use of a 20 minute exercise challenge to induce extra illness might provide insight into CFS, perhaps leading to identification of a biological marker of CFS. A biological marker, if found, may hint at a possible cause of CFS, and per-

haps also a possible treatment.

The study had two groups, one fitting the 1994 CFS definition, and a disease-free control group, matched by age and gender. Most participants were between the ages of 30 and 45. Data was also gathered for participants with allergies after an allergen challenge, and for everyone after a histamine challenge used for control purposes.

Three subjective data sets were gathered: daily ratings of 10 typical flu-like symptoms, weekly ratings of 32 symptoms, and weekly answers to questions related to five categories of fatigue (general, physical, mental, activity decrease, and motivation decrease). For objective data, blood was drawn multiple times after each challenge.

Several nonspecific immune system proteins were examined, including complement protein "C4a." In CFS patients, C4a, which has no known biological function, was found to be significantly elevated six hours after exercise and was correlated with worsened symptoms, but was not so elevated or so correlated in the control group. (Cont'd on pg. 3)

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President's Corner...

Volunteers Needed

All of us are overwhelmed as we live with chronic illness. Yet if we are to thrive as a support group, we need volunteers. If we don't have more volunteers, we will cut back services, or even shut down the non-profit corporation under which we operate.

We need a full slate of officers -- President, Vice-President, Secretary, and Treasurer. I'm currently covering the first three, and I need help. If suitable leadership comes forward, my talents are best suited for the Secretary role, and others can lead. We need a full set of board members. We are one short now, and some current board members want to yield to more involved members. We can use more substitute and regular callers. We need greeters at our meetings. We need help for the annual picnic and substitute help for meeting refreshments.

Our newsletter needs a staff. Nadine has been doing the newsletter single-handedly, and she needs help. We need people with writing talent who can summarize our lecture meetings. We also need people to contribute other ideas or articles for the newsletter (while providing full disclosure of information sources for copyright purposes).

Finally, we need a Speaker Committee to handle identifying, inviting, confirming, preparing, hosting, and thanking speakers. Also, being a CFS support group that only recently integrated FMS, we need to better meet the needs of our members with only fibromyalgia.

If you will help, please choose something consistent with your talents and get involved.

Appreciated Volunteers

Many thanks to **Karen Reese**, who retired from being a board member, secretary, and calling tree coordinator. Thanks also to **Gayle Pikna** for her recent temporary role as calling tree coordinator. Thanks to retiring callers **Catherine Sherman**, **Gail Souther**, **Alice Vigil**, and **Rochelle Winograd**. Thanks to **Lou Engle** for occasionally serving as a greeter.

Thanks to **Donna Chaney** for upgrading from a substitute caller to calling tree coordinator, and to **Bernice Taylor** for upgrading from a substitute caller to a regular caller. Thanks to **Jordon Orleans** and **Carron Taylor** for assisting with this newsletter, and to **Carron** for her efforts related to having Myra Preston come to Denver to speak to the Association in May.

We appreciate ongoing efforts of treasurer **Janice Pelster**, newsletter editor **Nadine Goranson**, refreshment coordinator **Cary Wettjen**, temporary speaker committee chairperson **Karen Reese**, callers **Jan Christensen**, **Dorothy Clingerman**, **Janet Hess**, **Don McKinstry** (also national contact person), **Steve McNichols**, **Robert Robertson**, and **Bonnie Sheppard**, and board members **Sarah Clausen**, **Janet Hess**, **Jeannie Muench**, **Janice Pelster**, **Kitty Sherback**, and **Tim Smith**. Also, thanks to those people in our group who are trying to start local area subgroups, and to **Jill Davis** for her efforts to produce a resource list.

Tim

Bristol - Cont'd from Page 1

C4a after exercise appears to be a possible marker of CFS and a possible mediator of fatigue. An ability to control C4a might help control CFS symptoms.

Bristol and Dr. Jones are requesting funding for three more years of related research, with special emphasis on what is activating the C4a protein.

Thanks to Jordan Orleans and Tim Smith for their joint effort to produce this article

Special Meeting: **May 18, 2002** **Brain Function and CFS/FMS**

We look forward in May to hearing from **Myra Preston**, of Charlotte, N.C. Myra is a Ph.D. Psychophysicologist specialized in Neuroscience. She believes CFS symptoms derive from abnormal brain function, and has spent over a decade developing testing and treatment for CFS patients.

Findings: She found CFS patients have an unusual amount of slow brainwaves during waking hours (when normal brains use higher frequency waves) causing "brain fog." As with brain damage or central nervous system diseases, CFS patients compensate by using inappropriate areas of the brain for simple tasks.

Testing: Dr. Preston uses a Quantitative Electroencephalogram (QEEG) diagnostic test to measure brain function in various parts of a CFS patient's brain. Without forcing a sleep-deprived

state as for regular EEGs, QEEGs also involve actively performing mental tasks. Pathological slow wave activity and/or phase reversals are evident in the QEEG test results, *and are useful for documenting disability.*

Analysis: After the QEEG test, individual assessment and extensive data analysis are used to produce a customized treatment program. For a "home based treatment" option, patients are then trained to operate neurotherapy equipment.

Treatment: Introduced in 1957, neurotherapy treatment has been used for treatment of various medical conditions such as seizure disorder, traumatic brain injury, depression, migraine headaches, Attention Deficit Disorder, and Gulf War Syndrome. Unlike other illnesses, CFS reduces tolerance to initial treatment, and affects different parts of the brain in different patients, both of which are handled by Myra's patented CFS testing and treatment protocols.

Think of neurotherapy as exercise for the brain. Like a physical exercise program, current conditioning is first assessed, in this case, using the QEEG test. Starting slowly, a customized workout regime then gradually builds brain function. If all goes well, brain function is steadily improved.

Potential Benefits: According to Myra, documented changes include: "improved concentration and short term memory, reduction or resolution of chronic and acute headaches, reduction in muscle and joint pain, decrease in sensitivity to sound and light, fewer letter and word reversals, increased

attention span, improvement in sleep patterns, better balance and muscle stamina, and a reduction in the amount of medications taken." She emphasizes neurotherapy is not a cure, but is a treatment.

Similar to physical therapy, the outcome is dependent on several factors, including the length of the CFS illness, extent of brainwave abnormalities, and participation of the patient. Dr. Preston reports improved function and increased quality of life in many of over 3,000 patients she has tested or treated since 1989. **Fibromyalgia:** Neurotherapy can also help FMS patients. Myra reports FMS patients have more localized brain abnormalities than CFS patients, and often respond more quickly to neurotherapy.

Disclaimer: Dr. Preston's approach to CFS treatment has been criticized. Skeptics view neurofeedback as a "high-tech fad". Dr. Cheney downplays the treatment process saying neurotherapy is "promising" rather than a "breakthrough."

As a matter of policy, the Rocky Mountain CFIDS/FMS Association does not endorse any service or medical hypothesis, nor do we dispense any medical advice or assume any liability for treatment undertaken by newsletter readers.

Denver Activity: After a two hour conference call in February with Dr. Preston and **Kim Phillips** (Dr. Preston's assistant and a CFS patient), several Association members signed up for the test or the test/treatment combination. As a result, Dr. Preston and Kim
(Cont'd on pg. 4)

Dr. Myra Preston

(Cont'd from page 3)

will come to Denver in May to perform QEEG tests, present their techniques and research at our regular monthly meeting, and provide "home based treatment" training.

An Association member purchased the \$3,500 neurotherapy machine, and offers to make it available for use by other Association members. Another member obtained office space for treatment. Contact Association member Carron Taylor at 303-985-8385, or Dr. Preston's office at 704-543-0427 with any questions, and/or visit website www.siberimaging.com.

Thanks to Carron Taylor and Tim Smith for their joint effort to produce this article.

Important Notice!



Save Your Non-Winning Scratch Lottery Tickets!

Just include a note with your name and phone number along with the non-winning tickets and send them to Janice Pelster at her address on the back of this newsletter. She'll take care of the rest. Our support group may be lucky enough to win this year. **But hurry, the drawing is soon!**

Dealing with Relapses

You are sitting in your bed in your pajamas at about 11:00 a.m., thinking, "Oh no, not again."

Most of us with Chronic Fatigue Syndrome or Fibromyalgia have been through this. Maybe we've been lucky enough to develop a daily routine. Maybe we've even been out with friends a few times. Perhaps we've been doing some errands or slowly working on a project. We might even have been feeling pretty good for a while. We feel lucky - appreciative - a part of things again - a least a bit.

And then it happens...relapse.

It could mean that we've "over" done it, but it doesn't have to. We may have been trying a new medication and dealing with its side effects. We may have stayed too long at that overdue lunch with our old friends. But often, we haven't done any of that. We've just woken up to find ourselves in a relapse. Back to the "living under water" feeling - the dragging around - often even increased hip and leg pain and decreased thinking ability. It's easy to get down in the dumps when this happens. How do we keep from getting really frustrated and depressed at times like this? A few things can be helpful:

1. Learn to ask for help.

Call a friend and say "I need you." Friends are often looking for a way to help, but don't know how.

2. Learn to let go of "doing".

Remind yourself that what you do on any particular day is not a reflection of who you are. You can "do" nothing, and actually be helping to heal yourself.

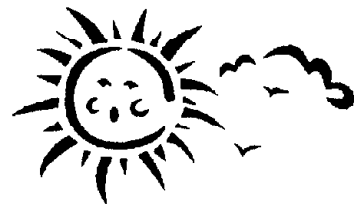
3. Remember the phrase: "This, too, shall pass."

The way our symptoms wax and wane, it's almost certain that something will change in the near future - even if it's something small - a little less pain, a little more calm, a little more energy - just a bit of a better day. Letting go of trying to control everything can be freeing.

4. Allow yourself to laugh.

Watch a funny movie or television program, or relax with a family member. Laughter and companionship can ease the pain and loneliness of chronic illness.

So the next time you wake up to that relapse, or feel it coming on, remember there are some small things you can do to help. You may not avoid your relapse, but you may keep it from overwhelming you.



Classical Homeopathy

Pat Taggart (720-635-0222) provided an overview of Classical Homeopathy at our January meeting. She feels homeopathy is especially valuable for chronic illnesses, attempting to cure not just help. The remainder of this article presents the *classical homeopathic view* of medicine.

Symptoms and Illness: Rather than suppressing symptoms, homeopathy attempts to address their underlying cause. Produced by the body in an effort to heal itself, symptoms mobilize the body's defenses. They have a purpose, if not to bring healing, at least to protect vital systems. Fighting symptoms defeats the body's attempt to heal itself.

Homeopathy is based on the Law of Similars: "like cures like." Its "remedies" *increase* symptoms, triggering the body's defenses to fight the root cause of illness. Such remedies give an "energy boost" to a body's natural ability to cure itself.

Remedies: A substance that causes a symptom is used to help the body cure the root cause of the symptom. Remedies are identified through "proving" – a costly and time-consuming process in which an overdose of a substance is given to healthy people to yield symptoms that are carefully noted. To achieve optimal results, all patient symptoms are matched to a single remedy.

Homeopathic remedies are inexpensive and come in either solid or liquid form. About 2000

remedies now exist. Remedies are prepared starting with a single, simple substance, typically a mineral or plant, which is highly diluted and energized through extensive pounding. Such dilute remedies are very safe – non-toxic, without side effects, non-addictive, and unable to cause an overdose. Their effectiveness is due to energy effects rather than biochemical effects. Remedies are proven one at a time, not in combination; combination remedies are therefore discouraged.

History: Developed about 200 years ago, homeopathy flourishes in other parts of the world, but has reportedly been squelched in the United States by the AMA and pharmaceutical companies.

Once identified, remedies for specific symptoms remain the same forever. They are effective since they are based on a fundamental understanding of the relationship between health and disease. They do not interfere with traditional western drugs.

However, driven by attempts to fight symptoms, traditional western drugs are changed from year to year with ever more bothersome side effects. Traditional drugs interfere with remedies, and patients on such medications take longer to heal.

Treatment Process: A classical homeopath uses an extensive interview to learn about current problems as well as past physical, mental, and emotional history. A significant pattern of illness is sought, and then matched to a pattern of symptoms related to a

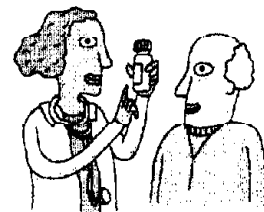
remedy. Once identified, the remedy is administered.

In subsequent visits, the remedy's effectiveness is evaluated. Depending on results, the same remedy of a different potency or a different remedy may be used. Sometimes one remedy is sufficient; other times multiple remedies are tried. Sometimes it takes years for crucial information to become known, finally leading to a successful remedy.

Professional help is usually required to enable people with chronic illness to find the right remedy. Sometimes a cure is not found, but help can be achieved even for cases of terminal illness.

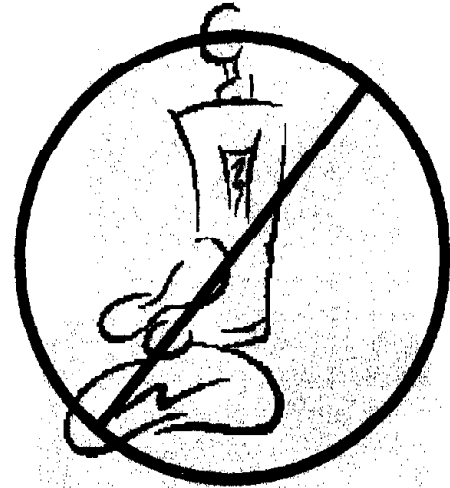
Summary: Finding a "correct" remedy can lead to deep, lasting, and profound changes. The ultimate goal is to cure the initial condition which prompted homeopathic treatment, while making the patient healthier all-around, improving physical, mental, and emotional functioning, providing a greater sense of well-being, improving energy, and yielding a profound and lasting change in health.

Homeopathy works with the body, is based on law of similars, uses extremely dilute substances for remedies, and is appropriate for any age person with any ailment. It is by-definition a holistic approach which treats the whole person.



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



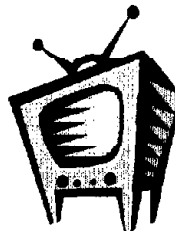
The CFS documentary film *I Remember Me*, directed by Kim Snyder, will soon be released on

home video. For information, contact Zeitgeist Films at 212-274-1989 or pear@zeitgeistfilm.com

The CFIDS Association of America has released the first national public service announcement (PSA) on CFIDS for television, featuring former U.S. Surgeon General Dr. David Satcher. The PSA emphasizes that CFS is a serious, complex medical disorder. For more information, or to view the announcement, go to: www.cfids.org/about/psa-intro.asp

A new magazine about Fibromyalgia premieres in May. This new magazine offers straightforward, insightful information and support. *Fibromyalgia Aware* is the first consumer magazine to address the needs and concerns of people affected by Fibromyalgia and overlapping conditions.

Published by the National Fibromyalgia Association three times a year, the magazine includes the latest news in research, a balanced approach to treatment options and a medical supplement for physicians and other health care professionals. For more information phone 714-921-0150, or go to: www.fmaware.org



Tim Smith Honored

Our President, **Tim Smith**, was recently honored with a CSN Champion Award in the category of "Newcomer." The CFIDS Support Network of America presented Tim with this award for his outstanding support of persons with CFIDS. In her nomination letter, **Janice Pelster** informed the Network of Tim's work in reviewing past financial reports, and updating legal paperwork for our group. He has also established connections with national organizations, and plans and facilitates monthly lectures and discussion programs. It was Tim's efforts that enabled our sponsorship of *I Remember Me* at a local film festival. We all owe a special debt to Tim for his ongoing achievements.

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 Qwest Voice Messaging Phone Call None

(Note: Qwest 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: _____

Date: _____

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**

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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.

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Meeting Schedule



May 18, 2002: Lecture Meeting: Myra Preston, Ph.D.

Dr. Preston is a Neurophysiologist from Charlotte, North Carolina. While in Denver, Dr. Preston will also provide Quantitative EEG brain wave mapping and home based neurotherapy training. For more details, please see page 3 of this newsletter.

June 15, 2002: Video Lecture Meeting: Blood Hypercoagulation with David Berg, M.S.

July 20, 2002: No Meeting - Enjoy your summer!

August 17, 2002: Annual Picnic - modified from earlier years.

Bring your own drinks; "finger foods" will be provided by the Association.
Find us at the outside covered patio behind Heitler Hall at National Jewish Center.

Meetings are held in Heitler Hall 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.