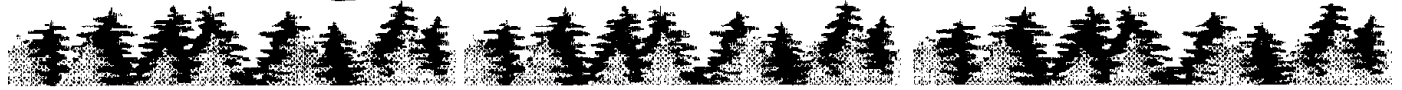


# Rocky Mtn CFS News



Volume 2, Issue 3

Fall 1999

## Recent Meetings

**Dr. Barbara Smith of CSU needs 10 more volunteers for her nutrition study! Call her at: (970) 491-6791 or email at: [basmith@lamar.colostate.edu](mailto:basmith@lamar.colostate.edu)**

Our **annual summer picnic** for members and their families was held at National Jewish Hospital on Saturday, August 20. Volunteers were awarded gift certificates as a token of appreciation for their hard work.

On **Sept. 18 Dr. Carl Grimes** talked about healthy habitats and how to avoid or eliminate toxins from your home. Look for notes on his talk in a future newsletter.

## National CFIDS Association News

**CDC Admits Wrongdoing.** The CDC finally admitted misallocation of CFS funds and the Director of the CDC, Dr. Jeffrey Kaplan, apologized to the CFIDS Assoc. of America for the situation. This occurred only after the Inspector General of Health and Human Services released an audit report showing CDC misconduct. In addition, Dr. William Reeves (chief of the CDC branch that studies CFS), filed a formal complaint against with CDC subsequent to applying for federal whistleblower protection; Dr. Reeves grievance states that he has experienced retaliatory actions from which he should be protected by the

“Whistleblower Act” (which protects federal employees who speak out about federal misconduct.) The General Accounting Office, in response to a request from Senator Harry Reid (D-NV), is conducting its own audit of CDC misconduct.

Audit reports indicate that the CDC used CFS funds not only to study measles, polio and other diseases, but also to balance the books at the end of the year. Congress had specifically requested that the monies allocated for CFS be spent on CFS only, a request with which the CDC did not comply.

Recommendations sent by the Chronic Fatigue Syndrome Coordinating Committee, including representatives from the CDC, to Secretary Shalala, included: restoring the full \$12.9 million misused from 1995-1998 over the years 2000-2003; requiring the CDC's director to oversee CFS spending and report quarterly to Congress and the CFSCC; keeping CFS in the Viral Exanthems and Herpesvirus Branch; conducting public education, particularly among primary care providers, about CFS; enhancing CDC accountability on CFS spending. CFSCC members indicate these are just the first steps to remedy the CDC's treatment of CFS education and research.

*Editor's Note: We are indebted to the CFIDS Assoc. for their persistence and determination in both uncovering and seeking remedies for CDC malfeasance of CFS funds.*

The **Ampligen Community Advisory Board (CAB)** meeting was postponed, according to their website. Check <http://www.cfids-cab.org> for details.

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## Nat'l CFIDS Assoc. News

The CFIDS Assoc. Exec. Director Kim Kenney has met with **new appointees at NIH's National Institute of Allergy and Infectious Diseases (NIAID)** which coordinates CFIDS research and grants, to discuss the CFIDS research portfolio as well as ongoing problems with the CFIDS research program at NIH.

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P.O. Box 220398, Charlotte, NC 28222-0398. Phone:  
1 (800) 442-3437

## Research News

The **Merck Manual of Diagnostic and Therapy**, the most widely used medical diagnostic resource, now lists CFS. The entry can be viewed online: <http://www.cais.net/cfs-news/merck.htm>

A group of U.K. researchers published a study in *Psychoneuroendocrinology* 1999; 24:759-68 in which they document their finding that small adrenal glands may be related to **poor adrenal functioning in CFIDS patients**. CFIDS patients had adrenal glands half the size of normal controls, while patients with major depression had enlarged adrenal glands (up to 70% enlarged.) Further studies must be done to determine if this finding applies to all CFS patients or only to a subset of those meeting the CDC's definition.

The *American Journal of Nursing*, March 1999, featured an article explaining CFS. "**Chronic Fatigue Syndrome: Do You Know What It Means?**", by Theresa Lynn Walker, BSN, RN, described the theories of causes, reported prevalence numbers and gave general treatment guidelines.

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## Sydney Australia ME/CFS Conference highlights:

**Garth Nicholson, PhD**, of the Institute for Molecular Medicine in Calif., gave a presentation on the **role of microorganism infections in CFS/ME, Fibromyalgia (FM), Rheumatoid Arthritis (RA) and Gulf War Illness (GWI)**.

Nicholson reported that mycoplasmas, chlamydia, Coxiella, Brucella, Borrelia and similar organisms are now considered important emerging pathogens in various chronic diseases.

His lab is finding mycoplasmal blood infections in 60% of CFS, 70% of FM, and about 50% of GWI and RA patients (cf 6% in healthy people.) Tests used are forensic polymerase chain reaction and nucleoprotein gene tracking; these tests are much more sensitive than ordinary serum antibody and other blood tests in common use. This is another indicator that psychological problems are *not* causing these illnesses.

His recommended treatment is long-term antibiotic therapy, 6 months continuously, then multiple 6 week cycles of doxycycline, Cipro, Zithromax or Biaxin. Patients feel worse initially (Herxheimer reaction), but a majority of patients benefit although recovery is slow and may not be complete. Professor Nicholson rules out placebo effects in his studies.

See the Institute's website for further information [www.immed.org](http://www.immed.org). Other doctors at the Conference expressed concern over long-term antibiotic use; development of resistant organisms was cited as a possible and undesirable outcome.

**Professor Kenny de Meirleir** spoke about the **2-5A dependant RNaseL enzyme and Ampligen**. The low molecular weight (LMW) enzyme appears to be unique to CFS (present in 95% of his CFS patients), and amounts vary with severity of symptoms. The RNaseL enzyme is induced by interferon production, which occurs only with infectious, mainly viral, illness, thus eliminating psychological causes. Ampligen causes a decrease in this abnormal enzyme and in

(Continued on page 3)

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follow-up studies of 2 - 4 years after Ampligen treatment, only 8% of patients had relapsed. The rest continued to do as well as they had on Ampligen. (Unfortunately for most of us, Ampligen is still experimental, thus unavailable.)

**Dr. John Martin** from City of Angels Medical Center in Los Angeles reported on his findings of a "stealth virus", a recombinant virus composed of part human Cytomegalovirus (CMV) particles and part african green monkey CMV. CFS patients testing positive for stealth virus are given the anti-viral Gancyclovir. He is not finding mycoplasma infections.(more info at [www.ccid.org](http://www.ccid.org))

**Dr. Neil McGregor** spoke about the improperly regulated pain mechanism in CFS; he also believes that the LMW 2-5A enzyme indicating viral activity predisposes CFS patients to secondary infections such as mycoplasmas. He says the viral problem must be cleared up or the treatment for secondary infections will not last.

**Psychologist Michael King** asked "which side of the desk is the neurosis on?" when doctors are unhappy about diagnosing a poorly understood physical disorder, and prefer to call it "psychosomatic." He said the "neurosis of omniscience" afflicting some doctors needs a cure.

Attorney **Simon Molesworth** encouraged all CFS sufferers to become politically active. Politicians listen when large numbers of people ask them to act in funding research. Mr. Molesworth also said that it is reprehensible when the primary approach to CFS is psychiatric at the expense of ignoring physiological treatment; he described this as medical malpractice, a legally actionable offense.

*Research News courtesy of the CFS-News electronic newsletter and the CFIDS Assoc. of America*  
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## Advocacy Network

See the CFIDS Assoc. of America's website for details <http://www.cfids.org> or email to [cfids@cfids.org](mailto:cfids@cfids.org)

## Local News

### Volunteers Needed!

We still need volunteers for:

- Mailing out newsletter
- callers

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 continue to provide information and services, including this newsletter, to members of the CFS community in this area. If you've already paid, Thank You!

### Save those Scratch Lottery Tickets!

Bring your losing scratch game Lottery tickets to the November meeting and turn them in. We will send them in to the Colorado Lottery for their annual charity drawing. The more tickets we submit, the better our chances of winning money for the group.

### Copier for Sale

Contact Jeannie Muench at 303 973-8094 for details.

### Audiotapes

To get an audiotape of the meeting, bring a blank 90 minute tape to exchange. The audio of the meeting will be dubbed to tape and later given to you.

### Email Addresses

Do you have an email address? Let Trish Melrose know at 303 665-9014 or [REDACTED]@flash.net.

We may send an electronic newsletter if enough members have email addresses.

## Dr. Paul Cheney Lecture to Dallas/Ft. Worth Support Group

by Nadine Goranson

On May 15th, noted CFS expert Dr. Paul Cheney spoke to the Dallas/Fort Worth CFS Support Group. During the first hour of his three-hour lecture, he covered the pathophysiology of the disease, telling audience members that CFS is a real disease and that he has the evidence to prove it.

According to Dr. Cheney, CFS is now more common than Diabetes or Multiple Sclerosis, and involves an overly activated immune system as well as a demonstrated injury to the central nervous system. His detailed lecture helped to illustrate the severity of the problems that plague people with CFS (PWCs). When asked the difference between Fibromyalgia and Chronic Fatigue Syndrome, Cheney noted the cognitive and neurological difficulties PWCs experience. He also pointed out that progressive exercise seems to help Fibromyalgia patients, but does not help PWCs because of the brain injury caused by the illness.

### Overactive Immune Pathway

Dr. Cheney explained the "natural immune pathway" which includes R-NaseL activity. This is an enzyme system that regulates protein synthesis and kills viruses. In PWCs, increased R-NaseL activity "chews up" messenger RNA, disabling the cells so that they cannot regulate protein or kill viruses. In addition, high activation of the R-NaseL system generates pain. He noted that in this disease, the rate of R-NaseL activity is higher than in cancer or even AIDS patients. The drug named Ampligen is known to regulate this pathway, and in recent tests, patients achieved normal protein synthesis and cell function after only 15 weeks on the drug.

### Deep Brain Injury

He also discussed the roles of SPECT scans of the brain in diagnosing CFS. SPECT scans measure the blood flow within the brain. In comparing different patients, he noted that depressed patients and normal patients' scans looked the same. However, depressed patients and CFS patients did *not* resemble each other, instead, CFS patients and AIDS dementia complex patients had similar SPECT scans. This information, along with MRI scans which often show lesioning of the central nervous system, lead Dr. Cheney to believe that there is "no doubt that this is a disease of the central nervous system." He went on to say that metabolic disturbances are marked in the brain, and can be seen if we use the right tools. The brain injury is focussed on the hypothalamus and leads to mitochondrial dysfunction.

According to Dr. Cheney, a primary reason for disability with CFS has to do with post-exercise cortisol response. In other words, PWCs can't do much without crashing, and he believes that treatment for this has to be directed at the brain. He mentioned the phenomenon of PWCs who "forget to breathe", which is a symptom of deep brain injury. It is due to the inability of the patient to regulate the diaphragmatic flow. Most PWCs naturally switch to non-aerobic metabolic means because they are simply unable to function aerobically. He emphasized that exercise can be very dangerous for the CFS patient, because "impaired mitochondria can damage the DNA." He also emphasized the universally low or non-functional levels of something called Glutathione in PWCs. The Glutathione concentration of a cell is in direct proportion to the energy available to the cell. The results of reduced Glutathione levels are rapid viral replication, energy drop and *detoxification failure*. Detoxification failure causes sensitivity to the environment - PWCs literally begin to be poisoned by their own bodies. In fact, normally, toxins are loaded into the brain, but in PWCs are often stored as fat,

(Continued on page 5)

just one way the body's defense mechanisms try to protect the brain. This explains why the great majority of PWCs experience weight gain.

### Three Phase Illness

Dr. Cheney views CFS as a three phase illness. In Phase 1, the patient feels the worst, and experiences high immune system activity coupled with cellular toxicity. Phase 2, often about five years later, is marked by cellular injury. He refers to this phase as the Toxic Phase. About five years later, Phase 3 begins, in which injuries to the central nervous system and mitochondrial DNA are evident. He believes that most damage to the brain and DNA takes place during the first two phases, and has developed treatment methods to try and reduce these effects. Interestingly, as the Phases progress, PWCs generally begin to feel less misery. A patient in Phase 3 often feels much better than a patient in Phase 1, though more damage has occurred in the brain and mitochondrial DNA. Dr. Cheney noted that most PWCs have learned to live within strict boundaries by the time they reach Phase 3 of the illness. Managing the illness helps them to maintain a more consistent level of functioning. In other words, they are not necessarily better, but have accepted their limitations and live within them.

### Being vs. Doing

He urges patients to develop a "being/healing" instead of a "doing/recovery" frame of mind. He emphasized that fighting Chronic Fatigic Syndromc simply does nothing to help the situation. His treatment methods include meditation to handle stress levels, as well as setting limits. Dr. Cheney's entire treatment protocol revolves around what he calls the "3 R Program" which refers to the "Remove/Repair/Replace" method of treatment. The protocol includes methods to resuscitate liver and gut function using whey protein, a good source of glutathione. It also includes detoxification and

mitochondrial protection, as well as protection of the central nervous system. He recommends an elimination diet, B-12 injections, and prescribes Klonopin in daytime and nighttime dosages. Currently, Dr. Cheney's private practice is located in North Carolina.

*This article was written by member Nadine Goranson, who saw Dr. Cheney's lecture. Nadine hopes someday to travel to see Dr. Cheney at his clinic. Thanks, Nadine, for a great article!*

## Inspirational Thoughts

When a man does a piece of work which is admired by all we say that it is wonderful; but when we see the changes of the day and night, the sun, the moon, and the stars in the sky, and the changing seasons upon the earth with their ripening fruits, anyone must realize that it is the work of someone more powerful than man.

*Chased-by-Bears, (1843-1915),  
Santee-Yanktonai Sioux*

Do you need a miracle today? Then expect one, take time to look for it, enjoy the moment, and thank God for it.

Bloom where you are planted.

*from The Little Book of Hope  
by Robert Schuller*



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Rocky Mountain CFIDS/FMS  
Association

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## 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: open  
Taping: John Bliss, Jr.  
Tape copies: Cindy Logan  
Greeter: open  
Videotaping: Rusty Dodson  
Doctor List: Beth Kerkstra  
Meeting Facilitator: Tim Smith

## Future Meeting

We meet the third Saturday of each month in  
Heitler Hall at National Jewish Hospital, Denver,  
from 1 - 3 pm.

### Meeting Schedule:

**October 16** — Group discussion "Nutrition and  
CFS: Food Choices, Food Restrictions and Sup-  
plementation." Dr. Barbara Smith from CSU's  
Dept of Food Science is expected to attend. Plan to  
attend and share your info with us!

**November 20** — Dr. Dennis Helfenstein, cog-  
nitive problems in CFS, esp. in relationships

**December 18** — no meeting. Happy Holidays!  
**January 15** — Dr. James Jones (tentative)