

ROCKY MOUNTAIN CFIDS/FMS ASSOCIATION

December 2000

Chronic Fatigue Syndrome Film Highlighted at Denver International Film Festival



The film, *I Remember Me*, written, produced and directed by Kim A. Snyder, was presented at the Denver International Film Festival in October. The Rocky Mountain CFIDS/FMS Association sponsored the presentation, which included a question and answer segment with Ms. Snyder after the film.

The documentary traces the director's journey as she struggles to understand her diagnosis of Chronic Fatigue Syndrome. Beginning in 1994, "Year One", Kim takes us through the onset of her illness, and the confusing and often frustrating attempts she made to find a diagnosis for her disabling condition. She chronicles the many tests and procedures she endured, before finally receiving her diagnosis of CFS. But her story doesn't end there.

After receiving her diagnosis, Kim experienced not only the devastation of learning to live with her debilitating illness, but also encountered the stigma often attached to the poorly named disease. As she moves through the ensuing years, she decides to visit Incline Village, Nevada, the site of a 1984/85 outbreak of CFS. Through interviews with Dr. Dan Peterson, (who was a physician at Incline Village at the time of the outbreak along with Dr. Paul Cheney), and other local personalities, she takes the viewers through the wide range of attitudes surrounding the illness. While Dr. Peterson is firm in his belief that CFS is a real disease, another local refers to the 1985 outbreak as being diagnosed by "quack doctors" and says CFS is mostly reported by "overweight women."

Kim's research takes her on a continuing journey. She reads studies from the 1950s which cite an outbreak of unexplained illness in Punta Gorda, Florida, and decides to go and talk to the subjects of those studies, to see how they are doing some 50 years later. The result is an engaging conversation with elder women who have survived the devastation of CFS and the label of "mass hysteria" which local physicians branded the outbreak in the 1950s.

Others interviewed in the film include Dr. David Bell, a well-known CFS researcher, as well as Blake Edwards, film producer, and Michelle Akers, World Cup Soccer star. Edwards and Akers both speak about the great difficulties Chronic Fatigue Syndrome brought to their successful careers. Snyder also visits with Stephen Paganetti, a high school senior who has been bedridden for two years, and has achieved a personal triumph by graduating from high school in spite of his illness.

After the film, Ms. Snyder answered questions from the audience, and spoke of her efforts to bring *I Remember Me* to television audiences. She is currently working to have the film shown on several venues, including PBS. She reported that the television program, Dateline, had recently requested a copy of the film. In addition, *I Remember Me* won Honorary Mention in the documentary category at the Hamptons International Film Festival, and the Encore People's Choice Award at the Denver International Film Festival, also in the documentary category. More information about the film, and the possibility of purchasing it on video, will be available soon at Kim Snyder's website: www.IRememberMe.com.



From the President...

Volunteer Retirement News

Lyn Smith, a recently elected Director, a Caller, and a past Treasurer for the association, retired from active volunteering. Callers **Ann Boyer**, **Rebecca Nicol**, **Alice Wycoff**, and **Cindy Logan**, also retired from active volunteering with the support group. Thanks to all these people for their past service to the association.

Board of Directors

Thanks to all who voted for our Board of Directors with timely return of your August surveys. 80 properly executed ballots were received. **Sarah Clausen**, **Janet Hess**, **Jeannie Muench**, **Janice Pelster**, **Karen Reese**, **Lyn Smith**, and **Tim Smith** were elected to the Board with each receiving over 90% of the vote. As provided in our Bylaws, **Tim Smith** was elected Chairman of the Board, and **Tim Smith**, **Karen Reese**, and **Janice Pelster** have been appointed by the Board to the offices of President, Secretary, and Treasurer, respectively.

The Board of Directors has voted to approve the following items:

1. Regarding association funds following the large lottery award in July, an affirmative vote of at least four (4) Directors is required to donate more than \$100 to any outside cause.
2. On the August survey, many people indicated a desire to use some of the lottery funds for CFS research at National Jewish Center. The need for a laptop computer was identified by Dr. James Jones. The board voted "yes" and \$2000 has been donated to NJC for a laptop computer to be used for CFS research under the direction of Dr. Jones.
3. \$250 has been used to fund postage for a mailing to over 700 people in the Denver area who are on Mary Trowbridge's FMS/CFS oriented mailing list. Our association benefited by providing all those people with information about our association, our meeting place, our regular meeting schedule, and our scheduled topics/speakers through January.
4. Following Lyn Smith's resignation from the board, in accordance with our Bylaws, **Kitty Sherback** was appointed to fill the vacancy on the board.

August Survey Results

Thanks to all who responded to the August survey, and to all who included dues and/or other donations. Eve-

ryone who has paid dues or other donations by check during this calendar year has been provided with a receipt for tax purposes. If you donated and haven't received your receipt, please notify **Janice Pelster**. We now have 129 people on the active Association list. Just over 100 inactive people remain in our data base, but have been removed from calling and mailing lists after failing to respond to multiple mail and/or phone contacts from us. Any of these people are welcome to reactivate by returning their August survey or otherwise contacting us.

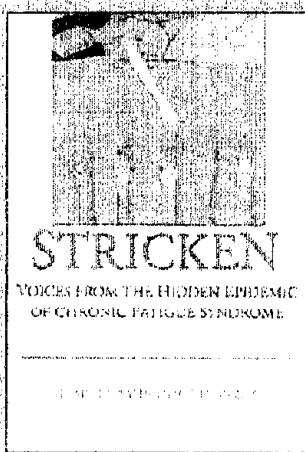
As a result of the survey, 31 previously called people, and another 19 people who haven't been receiving meeting notifications at all, are receiving either e-mail or voice-messaging meeting notifications. Thanks to **Jan Christensen**, **Dorothy Clingerman**, **Janet Hess**, **Don McKinstry**, **Steve McNichols**, **Roberta Robertson**, **Bonnie Sheppard**, **Katherine Sherman**, **Gail Souther**, **Alice Vigil**, and **Rochelle Winograd** for continuing as regular callers. They each have 5 to 7 people on their lists. And thanks to **Donna Chaney**, **Yetti Gruenler**, **Kitty Sherback**, and **Bernice Taylor** for volunteering to serve as substitute callers when needed.

Many people indicated they would be willing to call in for meeting announcements. Yet only five people chose calling-in as their only means of receiving meeting notifications. The officers decided not to pursue the effort and possible expense required to initiate and maintain a recorded announcement at this time. Sixty-four people indicated they would be interested in attending Patient Focus Discussion meetings. 13 said they would be the Focus Patient, and another 17 indicated possible interest in being the Focus Patient. 63 people indicated they wanted to receive mailings from Mary Trowbridge regarding other Denver area FMS/CFS support groups.

Thanks to the many people who recommended speakers, suggested topics, provided other comments, and volunteered to serve the association in various ways. All that information has not yet been transcribed and/or summarized. We will report those results to you in future newsletters. For those of you who volunteered but haven't yet been contacted, rest assured that your offers have not gone unnoticed. We just haven't become organized enough yet to get you mobilized. A special thanks to **Nadine Goranson** for volunteering to become our newsletter editor.

Unfortunately, except for two very restricted offers to help in particular ways, we must report that nobody volunteered to serve on a speaker committee or be

its chairperson. We urgently need members willing to serve on a committee responsible for scheduling speakers for lecture meetings. If people don't come forward for this function, the frequency of lecture meetings may be significantly reduced.



New CFS Book Available

In October, Haworth Press published a new book about Chronic Fatigue Syndrome. *Stricken: Voices from the Hidden Epidemic of Chronic Fatigue Syndrome*, edited by Peggy Munson, is a collection of stories from people whose lives have been

personally touched by CFS. Among the contributors is the new editor of the Rocky Mountain CFIDS/FMS Association's newsletter, **Nadine Goranson**. Nadine's story, "Silent Trespass", chronicles lessons she learned in the early stages of her illness. While the book is available at barnesandnoble.com and amazon.com, the book may also be ordered at 35% off the list price through Nadine. If you are interested, drop her an e-mail at: engoranson@uswest.net

More Books...

The Arthritis Foundation has released several new books to assist patients coping with chronic illness. *Celebrate Life - New Attitudes for Living with Chronic Illness*, was written by Kathleen Lewis, who lives with several chronic illnesses. The book covers such topics as: coping with loss, embracing everyday joys, communicating effectively with your doctor, and learning to honestly answer the troubling question, "How are you?"

Toward Healthy Living, a Wellness Journal, is designed to help patients record feelings. It also includes daily pain and mood scales, and inspirational quotes to help people with any kind of chronic illness improve their outlook on life.

Do you have trouble remembering what to tell your doc-



tor at your regular office visits? How many times have you left "the list" at home, and drawn a blank when asked what your latest symptoms are? *Health Organizer - A Personal Health Care Record* can help you keep track of the details. This book helps you keep an organized record of your symptoms and progress, so you and your physician can work together to manage your care.

Arthritis Foundation books are available at bookstores everywhere.

In the News

On October 2, 2000, **U.S. News & World Report** magazine ran a story on Chronic Fatigue Syndrome. Entitled "In the Heart, Not the Head," by Rachel K. Sobel. It addressed the recent research done by Dr. Martin Lerner, who claims to have found new evidence that CFS is a result of heart damage caused by Epstein-Barr virus and cytomegalovirus. (See the related story under "Research" on page 5.)

"**Focus on the Family**," a Christian radio show aired a three-part series on CFS October 16th, 17th and 18th. Each program was 30 minutes in length and was heard on over 1,800 radio stations in America. (See page 6 to order audio tapes of the broadcast.)

During **NBC's coverage of the Sydney Olympics**, 400-meter swimmer Tom Dolan spoke openly about his battle with CFS. He informed reporters that he was concerned about his lungs and weakness, and that he had oxygen tanks waiting for him in his room. Dolan went on to win the final.

Dennis DeYoung of the rock band, **Styx**, sued his fellow band members in Chicago for touring without him, using the name of the band he co-founded 35 years ago. He has been ill with CFS since at least the summer of 1999.

National Public Radio (NPR), recently aired an interview with Keith Jarrett on its popular program, "**Fresh Air**." Jarrett, a well-known jazz and classical pianist, spoke about his four-year battle with CFS, which threatened to end his performing career at the age of 50. During the interview, he criticized the name of the illness, saying he uses the name under protest, as it does nothing to describe his disabling condition. He is currently undergoing treatment which he describes as "conventional medicine used unconventionally" and which, he admits, has serious side effects. His first recording since becoming ill is entitled, "The Melody At Night, With You," and was recorded at his home studio for his wife.

In the “News”...

The New Yorker Covers Fibromyalgia:

**Balanced Reporting
or Bias Disguised as Logic?**

Copyrighted Material Removed...

Copyrighted Material Removed...

- Lisa Lorden

(Excerpted from her article at <http://chronicfatigue.About.com>)

Letters in response to Jerome Groopman's article can be sent to: "The Mail," The New Yorker, 4 Times Square, New York, NY 10056 or fax your letter to (212) 286-5047.

"Never go to a doctor whose office plants have died."

- Erma Bombeck

Research News

Lone voice proponent of single cause theory of Chronic Fatigue Syndrome

Excerpts from an article by Deborah Cooper at ImmuneSupport.com

Viral-induced heart damage is the single cause of CFS according to over a decade of research by Dr. A. Martin Lerner, a board certified internist who recently presented his latest findings at The American Society of Microbiology. Since 1988, Lerner has investigated the theory that two viruses belonging to the same viral family damage the heart muscle, resulting in CFS.

In an interview with ImmuneSupport.com, Lerner, who practices at William Beaumont Hospital in Royal Oak, Michigan, explained that his findings "are remarkable. The viruses that seem to be involved are two very sophisticated members of the herpes virus family, gamma and beta virus, also known as Epstein Barr Virus and cytomegalovirus."

Lerner is emphatically not referring to the herpes virus known as HHV6, or 8. In fact, contrary to several other avenues of research currently being explored, Lerner states that "I do not believe that HHV6 is important in any major way at all. Certainly not in the subset of patients my collaborators and I have studied."

Several studies support Lerner's theory, the first of which was published in the peer-reviewed journal Chest. This study observed that patients with CFS all had abnormal cardiac readings. From there, open studies were conducted with control groups, which were then repeated in a double-blind study in 1997. In this study, which Lerner himself was not involved in, 60 CFS patients with no known heart disease blindly had halter monitors read by independent cardiologists. Over 95% of the patients with CFS had abnormal halter monitors, meaning that they had heart damage.

If proven, Lerner's theory is hugely significant for the way CFS could be treated. In fact, Lerner, a CFS patient himself, was the first to try high doses of potent antiviral drugs, such as valacyclovir (brand name Valtrex) and ganciclovir (Cytovene). He is now involved in a double-blind placebo controlled study of valacyclovir's effects on Epstein-Barr Virus. The pharmaceutical company Glaxo Wellcome is funding the study, and Lerner predicts it will conclude in about a year.

Meeting News

On September 16th, Kathryn Castleberry spoke at our Association monthly meeting about Chiari Malformation and Cervical Spine Stenosis.

Chiari Malformation is a condition in which the cerebellum portion of the brain protrudes down into the spinal canal. **Cervical Spinal Stenosis** occurs when the space at the base of the skull is too small for the spinal cord, causing pressure and affecting spinal fluid flow.

Kathryn has personal experience with both conditions, and reported that her symptoms included severe headaches at the base of the skull, tandem walking (a slow gait with legs far apart and knees just slightly bent), difficulty swallowing, memory loss, fainting upon sitting up, fatigue, restricted neck movement, vertigo, eye pressure, wavy vision, tingling in sinuses and extremities, and more. Because many of the symptoms of both of these disorders are similar to CFIDS/FMS symptoms, it is important for patients to consider an MRI of the brain and cervical spine to rule out either condition. However, Kathryn cautions that it is difficult to find professionals trained in reading these MRIs.

Corrective surgery is available, though controversy about the risks involved abounds. Dr. Dan Heffez who performed Kathryn's surgery, was spotlighted on Dateline recently in a story citing Chiari Malformation and Spinal Stenosis as possible causes of Chronic Fatigue Syndrome. More information can be found at the website of the Chicago Institute of Neurosurgery and Neuroresearch: www.cinn.org

Editor's Note:

Have an idea or article for the newsletter? Submissions on CFS/FMS topics are welcome. You can send original articles or current news to [redacted]@uswest.net, or call me at (303) 678-0531. (Articles may be edited for clarity or space considerations.)

Nadine Goranson

Notice: If you have any materials checked out from the support group's library, please return them by mail or at a regular monthly meeting. Thank You.

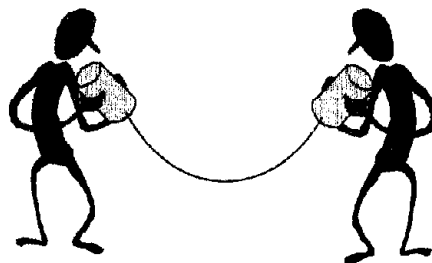
Notice: Focus on the Family's three half-hour programs about CFS are available on tape for \$7.00. Contact Focus at www.family.org or 1-800-AFamily (1-800-232-6459).



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.

A Note About Voice Messaging

In an effort to streamline our calling tree for upcoming meetings, some of us use U.S. West Voice Messaging. This service allows one person to enter phone numbers a single time, then send a single recorded message out to all people on the phone list. It's a real time saver. If you have Voice Messaging, (and are in the local toll-free area) we can add you to our Calling Tree list for meeting reminders if you'd like. Just circle "Voice Messaging" on the form to the right, and send it to the address at the bottom of the form. This only works for U.S. West Voice Messaging which is a service built into your phone line. If you don't have Voice Messaging, but you'd like us to leave a message on your answering machine, circle "Phone Call" on the form.



ASSOCIATION INFORMATION

LEADERSHIP TEAM

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

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

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

Nadine Goranson.....Newsletter Editor
 [redacted]@uswest.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. 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 \$ _____

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: _____

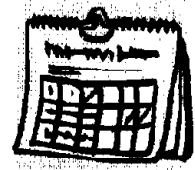
Please detach and send to:
 (make checks payable to:)

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

Meeting Schedule

December 16, 2000: No meeting. Happy Holidays!

January 20, 2001: Lecture meeting: Dr. James F. Jones



Dr. James F. Jones of National Jewish Center, a nationally known CFS expert, will provide his yearly update on CFS research and any other notable CFS related news. This meeting will focus mainly on CFS, not FMS.

February 17, 2001: Video of Lecture by Dr. Paul Cheney - (1st half)

We will show a video entitled: "The Pathophysiology, Diagnosis and Treatment of CFIDS." by noted CFS expert, Dr. Paul Cheney, who spoke to the Dallas/Fort Worth CFS Support Group in May of 1999. Half will be shown in February, and half in March, each with discussion afterwards.

March 17, 2001: Video of Lecture by Dr. Paul Cheney - (2nd half)

☆☆☆☆ *NOTE: Due to another conference in Hettler Hall, on this date only, ☆☆☆☆*
☆☆☆☆ *we will meet in combined room L106/L109 off of the cafeteria. ☆☆☆☆*

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.)

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

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