



Bergen CFS-FM Support Group Newsletter

Meeting Report

The meeting was again held at the New Milford Public Library. It was an open forum discussion. Mr. Shin, a qi energy healer who spoke at a previous meeting, returned to this meeting offering mini sessions for those in attendance. They were very appreciative to be able to try this alternative therapy – especially those who have had little success with conventional medicine. The Bergen CFS-FM Support Group and our parent organization, the NJCFSA, so not necessarily endorse any specific treatments, but occasionally make information available for our members to consider.

The **BIG** news today is that the Bergen CFS-FM Support Group has a new home. The following message is from co-leader, Judy Machacek.

*“I am happy to announce that we have been warmly welcomed by the **YW/YMCA of Ridgewood** New Jersey as a permanent location for our future Bergen Support Group Meetings. We will have our first meeting on May 18, 2008 from 2 to 4 pm in the Conference Room on the first floor. You do not have to be a member of the YW/YMCA to join or participate in our group.*”

Directions: Route 17 North or South to Linwood Ave. Follow Linwood Ave Westbound toward Ridgewood and past the Valley Hospital-about 2 miles. At the end of Linwood, is a T in the road. This is Oak Street. Turn left onto Oak and go one or two blocks to enter the parking lot. There is plenty of free parking. You can walk up to the first floor Lobby or take an elevator. Please check in at the desk and tell them you are a member of the Bergen CFS/FM Support Group. They will direct you to the meeting room. (You may also travel Rt. 17 to Ridgewood Avenue, about 2 miles to Oak Street. Turn Right and go 2 blocks until you see the YW/YMCA on your left.)

We look forward to welcoming back all our regular attendees and welcome anyone who wants to learn more about coping with Chronic Fatigue Syndrome and Fibromyalgia.”

CFS Awareness Month

The following is a report that NJCFSA Board member, Dr. Rosemary Underhill submitted to the NJCFSA board. It is reprinted here with her permission. Thank you Dr. Underhill for this explanation.

A Vote for a fair name for Chronic Fatigue Syndrome

I wish to inform members of our board about some things, which are ongoing in the wider world, of the community of people who treat, research, write about, and advocate for, people with Chronic Fatigue Syndrome.

Rich Carson, has set up a web site www.afairname.org calling for a fair name for Chronic Fatigue Syndrome. Rich, as many of us know, is himself a patient, an entrepreneur, and an advocate. He is a very long time supporter of changing the name of the illness. He has asked that as many people as possible take the opportunity to vote in May, on his web site for a “fair name.” The vote will not be in fact for a new name for the disease, but a vote for or against using the acronym **ME/CFS** for it. The ME part stands for Myalgic (muscular pain) Encephalomyelitis (inflammation of the brain and spinal cord), or Myalgic Encephalomyelopathy (disease of the brain and spinal cord)...more on this later. The name Myalgic Encephalomyelitis was coined in 1956 to describe an epidemic disease which had occurred in the Royal Free hospital in London. This name has been used worldwide since that time. Rich Carson points out that ME/CFS reflects the science of the illness and gives it credibility. (It is also more difficult to shorten to just “chronic fatigue”.)

I will summarize the background of this particular recommended name change.

In Jan 2007, at the last IACFS conference, Rich Carson arranged a meeting with several famous doctors and scientists in the field of CFS. They included: **Drs. Lucinda Bateman, David Bell, Paul Cheney, Leonard Jason, Tony Komaroff, Nancy Klimas, Chuck Lapp and Dan Peterson.** This meeting resulted in a unanimous agreement to endorse using the acronym ME/CFS instead of CFS and they recommended adding ME to the IACFS acronym. The group also agreed to be members of a panel of doctors and scientists who are sponsoring the name change to ME/CFS. There is a much larger group of activists including Eileen, who are actively trying to encourage this change in the wider ME/CFS community.

The story of the name for CFS dates back to the late 1980s. A committee of the CDC coined the name Chronic Fatigue Syndrome for a disease, which at that time was causing an epidemic in the Lake Tahoe area. This committee said and the CDC continues to say that it was a new disease. Some members of that CDC committee resigned because they disagreed. Many epidemics of the same disease had previously appeared in various parts of the U.S. and around the world under different names. Because of wide spread dislike of the fatigue word in the name, in the late 1990s the Federal CFS coordinating committee set up a name change committee, which consisted of many well known doctors and scientists in the CFS world. In Sept. 2001, the name Neuro-endocrine-immune dysfunction was eventually proposed, against the wishes of many patients. However, in Sept. 2003, the renamed CFS Advisory Committee refused to accept this new name because they said that the disease was not sufficiently understood.

Meanwhile, in Jan. 2003 an international panel of doctors and scientists published a new Canadian Clinical case definition for Myalgic Encephalomyelitis and Chronic Fatigue Syndrome. The abstract stated that throughout the paper the two names were used interchangeably and the illness was referred to as ME/CFS. In 2006, an IACFS working group of well-known scientists and clinicians published a Pediatric case definition for ME/CFS. Again, this acronym was used throughout the paper. We ourselves have been using the acronym ME/CFS for all our recent publications. Because we quote the new Canadian Clinical Case Definition and the Pediatric case definition in our fact sheets, we need to use the same acronym as was used in these case definitions. Unfortunately, we can't get rid of the CFS from this acronym, because it is used in legal documents such as SS disability documents. Also, many researchers have used the 1994 International case definition, which calls the illness Chronic Fatigue Syndrome, so this name has been often used in the medical literature of the past 20 years.

Being politics, there is another wrinkle:

Some people want the E part of the ME to stand for Encephalomyelopathy, instead of Encephalomyelitis. They say that "itis" means inflammation and there is no evidence of inflammation in the brain of ME/CFS patients. Whereas they say that "opathy" would be better, because it means "diseased," but doesn't specify what sort of disease.

The opposing point of view states that actually evidence of inflammation has been found around the blood vessels in the brain of CFS patients who have died. Also, some people are fearful that CDC and others could use "Encephalomyelopathy" to mean neurosis or psychological problems. Using the acronym ME/CFS ignores the difference of opinion about -itis and -opathy.

I [Dr. Underhill] personally think that "itis" should be used. It is historically correct. It is used worldwide, and has been used in a large amount of the medical literature for over 60 years. Just because information about a disease changes you don't necessarily need to change the name. For example, Malaria means "bad air." We all know that the disease Malaria is not caused by bad air. We have seen many names and acronyms come and go, and will have to wait and see if this one sticks. Meanwhile, it is a small step forward with a longer-term aim of getting rid of the "fatigue" word. If you wish to do so, please vote for the fair name ME/CFS: Go to the web site, read the petition and hopefully they will be ready for us to vote on it in May. The web address is www.afairname.org.

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May 12th is ME/CFS Awareness Day and the month of May is ME/CFS month. It is a time to reach out to our family and friends to help them to understand – or at least accept – the limitations this illness causes. We need to remind them that WE have not changed and that our desires and dreams, our very being is still intact. It is an illness, like any other, that sometimes forces us to alter or postpone some of our plans. Governor Corzine has proclaimed May to be CFS Awareness month and his proclamation follows.



STATE OF NEW JERSEY
EXECUTIVE DEPARTMENT

Proclamation

WHEREAS, *Chronic Fatigue Syndrome (CFS), also called chronic fatigue and immune dysfunction syndrome, is a complex and debilitating illness often, interrupting the education or employment of patients, complicating their family and social lives, and causing an accumulation of medical expenses; and*

WHEREAS, *Chronic Fatigue Syndrome is a complex illness that affects the brain and many different body systems and is characterized by disabling fatigue, a variety of neurological problems and other physical dysfunctions, often sufficient to qualify severely afflicted patients for Social Security Disability and/or private long-term disability insurance benefits; and*

WHEREAS, *Chronic Fatigue Syndrome symptoms include severe exhaustion, widespread joint and muscle pain, cognitive difficulties and relapse after previously well-tolerated physical or mental exertion; and*

WHEREAS, *the Centers for Disease Control and Prevention (CDC) has designated CFS as a "serious public health concern," which affects 1,000,000 American adults and teens, and the National Institutes of Health (NIH) continues to investigate and document the frequency and spread of this syndrome; and*

WHEREAS, *children and adolescents with Chronic Fatigue Syndrome face many physical, social and academic challenges; can be classified as disabled; and may be entitled to educational services under the Individuals with Disabilities Act or Section 504 of the Rehabilitation Act of 1973; and*

WHEREAS, *the State of New Jersey is pleased to join the New Jersey Chronic Fatigue Syndrome Association (NJCFSA, Inc.), a non-profit corporation promoting programs and support groups throughout the State, and with all CFS patients who must struggle daily to cope with illness and disability, in celebrating a special month devoted to increasing knowledge and understanding about CFS and in supporting valuable research in this State into its causes and cure;*

NOW, THEREFORE, I, JON S. CORZINE, Governor of the State of New Jersey, do hereby proclaim

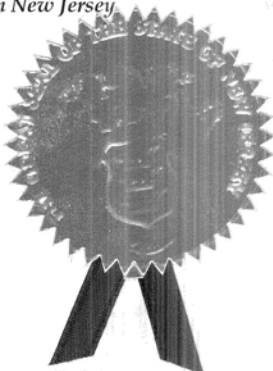
MAY 2008

AS

CHRONIC FATIGUE SYNDROME AWARENESS MONTH

in New Jersey

GIVEN, under my hand and the Great Seal of the State of New Jersey, this first day of May in the year two thousand eight, the two hundred thirty-second year of the Independence of the United States.



BY THE GOVERNOR:

GOVERNOR

Nina Mitchell Wells

NINA MITCHELL WELLS
SECRETARY OF STATE

FM Awareness

May is also FM Awareness month and National Fibromyalgia Association <http://www.fmaware.org> has many activities listed on their website. The following is an activity that takes place in Union County, NJ

Name of Event: Fibromyalgia: Caring By Sharing Awareness

Host of Event: Union County Fibromyalgia Support Connec.

Date of Event: 05/17/2008

Start Time of Event: 10:30 am

End Time of Event: 2:00 pm

Location of Event: Rahway Public Library

2 City Hall Plaza

Rahway, NJ 07065

Cost of Event: Donations Accepted

Event Contact: Lillian Aragoes-Enda, Group Leader

Event Contact Email: Lendaed@aol.com

Event Contact Phone Number: 732-499-9028

Description of Event: Showing of "Living With Fibromyalgia" DVD Guest Speakers Proclamation Testimonials Fibromyalgia Q&A Session Reception

Social

Social Director, Frank Kawa, has set a date for a gathering

Wednesday May 7th

Luncheon

at

The Seville Diner

289 Broadway

Westwood

The group will be there from 1:30 PM until about 3 PM.

Just show up.

If you have any questions or wish to let Frank know you are coming, you can call him at 201-768-4111.

You do not need to contact Frank to attend.

CFS and FM Awareness Activities

In previous years, Ma 12th has been CFS Lobby Day in Washington. This year that event will not be held but Virtual Lobby Day will be held as usual.

For those of you with Internet access, please consider going to www.cfids.org and participating in the Grassroots Action Center Activities. You will find a series of pre-written letters that you can send via email to your senators, representatives, the Secretary of Health, the directors of the NIH & CDC, and local media. There is space in the letter where you can add a personal touch if you want to do so.

The following message is form www.cfids.org.

Virtual Lobby Day #5: Coming Soon!

On Monday, May 5, the CFIDS Association of America will launch its 5th Annual Virtual Lobby Day, strengthening the calls to action made during a series of events occurring next week in Washington, D.C. Read more about what's going on in our nation's capital in the latest issue of *CFIDSLink*, available on our website at <http://www.cfids.org/archives/2006-2010-cfidslink/april-2008.asp>.

These virtual activities will also bolster other education events occurring this month in conjunction with International CFIDS/CFS/ME Awareness Day, recognized worldwide on May 12. Please plan to participate this year to ensure that timely, orchestrated, powerful messages are sent to people who have the power and possibility to change policy and perceptions about CFS.

Marissa's 4th Annual Gift Auction

The 2008 Gift Auction to benefit the NJCFSA

Saturday May 10, 2008

VFW Post 2639,

1515 Corlies Avenue Neptune, NJ.

Doors open at 6:30 PM. Drawing: 7:30 PM

Admission: \$7.00 in advance, \$10 at the door

Adults only

Admission includes 1 sheet of regular-basket tickets, coffee, tea and cookies.

Additional tickets and larger-basket tickets available at an additional cost

All proceeds go to NJCFSA

VFW Post 2639 generously donates the use of their hall each year - as well as making monetary contributions for the purchase of some of the larger items. VFW Members also generously donate their time.

Over \$10,000 has been raised to benefit the NJCFSA

If you, or a business owner you know, would be willing to donate an item or gift certificate, please contact us. All help is greatly appreciated. Donations of S&H Greenpoints (Foodtown) are requested as they help to purchase items for the auction.

For More info: call Fayth or Marissa Newell 732-775-9326

Please mark the date on your calendars and join us.

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"An Evening of Stars!"

NJCFSA's Gala Benefit to raise awareness for CFS/ME

Honoring

Jon Sterling - Founder, 1st President of NJCFSA

Betty McConnell - Founder, NJCFSA Librarian and 2nd VP

Barbara Comerford, Esq. - Former NJCFSA trustee, Disability Attorney

Saturday, May 17th, 2008 5-9 PM

Sofia Restaurant

9314 Amherst Avenue, Margate New Jersey

(609) 822-9111

For information and tickets contact

Dominique Soeldner: Dominique.njcfsa@gmail.com

or send to

NJCFSA

PO Box 477

Florham Park, NJ 07932

or call

NJCFSA Helpline: 888-835-3677

Tickets - \$100 each - Limited to 250 seats

Proceeds go to the H.S. Scholarship, Medical School Scholarship and Research Funds

Clinical Trials

Clinical trials <http://www.cfids.org/about-cfids/clinical-trials.asp#duke>

A New Study for Fibromyalgia Patients

Dr. Lucinda Bateman is actively seeking Fibromyalgia patients, ages 18-70, to participate in clinical research studies of three investigational drugs for the treatment of Fibromyalgia. If you are interested, call Dr. Bateman's office (801-359-7400) and talk to Ali Allen, RN, research coordinator, or others on the research team, to learn more about the drug studies currently underway. Qualified participants receive study-related physician visits, lab evaluations, and the investigational medication at no cost.

Dr. Bateman is in Utah and I don't know if this is open to those who are not in the local area.

Next Meeting

The next meeting will be Sunday May 18th from 2-4 PM at the Ridgewood YMCA [directions included in this newsletter]. We look forward to seeing you at our new location.

This newsletter is intended for CFS patients in the area of this support group. The purpose is to share information and support. If you have questions about meetings please contact: Pat LaRosa at pat.njcfsa@larosas.net, Nancy Visocki at ngv.njcfsa@verizon.net, Judy Machacek at judymachacek@msn.com or Frank Kawa at 201-768-4111.