



Bergen CFS-FM Support Group Newsletter

Meeting Report

The December meeting was held at the home of Frank Kawa. Pascack Valley Hospital had closed in November and a new site had not yet been secured. The annual holiday gathering gave those who braved the inclement weather a chance to relax and celebrate together. The participants to set a table fit for a feast.

Now the group looks forward to 2008. May it bring each of you health and happiness. Perhaps this will be the year of the cure.

Meeting Site

WE HAVE A NEW HOME!

We are excited to announce that after very extensive searching by co-leader Judy Machacek, we have a location for our meetings. Holy Name Hospital recently opened an offsite facility

**HNH Fitness Center
514 Kinderkamack Road
Oradell, NJ 07649**

It is situated between Oradell Avenue and Soldier Hill Road and is directly across the street from the AAA North Jersey-Oradell. If you are not familiar with the area, you can get directions to the Fitness Center at www.mapquest.com or at the site of their neighbor across the street, AAA North Jersey – Oradell

<http://ww1.aaa.com/scripts/WebObjects.dll/AAAOnline.woa/3008/wo/pgE4f41CWnMVPmcbMf5bOM/4.9.13.4.15.1.3.1> or contact. Contact information can be found at the end of this newsletter.

Please park in the lot behind the Fitness Center and enter through the rear door. Go to the desk in the Lobby and tell them you are attending the Bergen CFS-FM Support Group meeting. You will be asked to sign in on a sheet that is specific to our meeting. You will then be directed to the conference room off to the left. The facility is handicapped accessible. There is ample parking and the walking distance is quite short. In addition to being a fitness center, it is also a physical therapy site, so physical limitations are not an issue.

You are welcome to bring your own refreshments – please remember to clean up. There are no facilities for coffee, tea or water, so please bring your own water, juice, etc.

Social

Social Director, Frank Kawa, has set a date for the first gathering of 2008

Wednesday January 2nd

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.

Toward Better Care

Closing Gaps for Better Care

www.chronicfaique.about.com/b/7/12/17/closing-gaps-for-better-care.htm

Monday December 17, 2007

Anyone who's waited months for a doctor to discover why they were in pain, only to be told "you have fibromyalgia -- sorry, there's not much I can do for you" knows full well about "gaps" in knowledge and treatment when it comes to this mysterious and misunderstood condition. Now, a new group is trying to close those gaps. MJ Consulting Group, the National Fibromyalgia Association (NFA) and Gullapalli and Associates (G&A) have put together the Advisory Council on Fibromyalgia Education (ACFE). The group is made up of experts from several fields and says it's identified significant gaps and barriers when it comes to the identification, diagnosis and management of fibromyalgia syndrome (FMS).

"Each of these barriers contributes to poor patient care and outcomes. Ideally, the management of patients with fibromyalgia syndrome should be individualized, multimodal, multidisciplinary, and should be expected to extend over weeks to months with a continuum of care during that time," says Dr. I Jon Russell, associate professor of medicine at the University of Texas Health Science Center and member of the ACFE.

The group's goal is now to look for reasons behind the barriers and find ways to solve them. The focus will be on educating the medical community about the broad array of new FMS developments.

Fibromyalgia is only the first condition the group plans to tackle. Also on the agenda: chronic fatigue syndrome, chronic headache and temporomandibular joint syndrome (TMJ).

Toward a Possible Diagnostic Test

Can exercise help diagnose chronic fatigue?

<http://chronicfatigue.about.com/b/2007/12/22/can-exercise-help-diagnose-chronic-fatigue.htm>

Saturday December 22, 2007

Part of the reason some people, doctors included, don't believe in chronic fatigue syndrome is that it's a "diagnosis of exclusion" - rule out everything else that could cause your symptoms and it must be CFS! (That's a misperception and over simplification...) But now, a group of researchers hopes to find a better path to diagnosis by studying exercise.

One of CFS's primary symptoms goes by the mouthful "post exertional malaise." What that means is getting really worn out after even moderate exercise or activity. Experts in exercise physiology from the University of Calgary's Faculty of Kinesiology say studying the way people recover from exertion can provide objective evidence of CFS.

Here's how they say it works: a patient rides a stationary bike until he or she is fatigued. Then, researchers take several measurements and (here's where it really gets exciting!) a blood sample. Why blood? To test it for lactate, which builds up in your body when you exercise. The next day, the patient goes back and does it again. Someone without CFS will likely be able to match the previous performance, while someone with CFS still hasn't recovered from the first bike ride and therefore won't do as well. Researchers say several measurements, including the blood test, will show the actual physiological differences in people with chronic fatigue.

Let's hope they're right, so we can finally have a better way to diagnose CFS and help people with it escape the stigma of the diagnosis by exclusion.

[Editor's note: We do not necessarily endorse this, but present it for your information about current research.]

Learning about CFS-FM

Have you thought about how you might spend some of your time this winter...or how you might learn more about your illness? DO you know what the leading researchers are saying about treatments? You may have been surfing the net seeking answers, but there is a lot conflicting information. Perhaps you are too ill to attend conferences and even when you do, you may not remember what you heard because of cognitive issues. Consider checking out the amazing list of materials available in the NJCFSA Library. You can peruse the list of offerings at www.njcfsa.org. Click on "Library" in the left column. NJCFS members can borrow materials for modest shipping and handling fee. Membership is \$25 and membership forms can be found at the NJCFSA website.

Next Meeting

The next meeting will be Sunday January 19th from 2-4 PM at the HNH Fitness Center. It is an open discussion meeting.

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.