



Bergen ME/CFS-FM Support Group Newsletter

Meeting Report

We were more fortunate with the weather this month than in December. It did snow the night before the meeting, but the morning was sunny and just warm enough to prevent slippery driving. This meeting was open-discussion format.

Among the topics discussed was dizziness. As with all symptoms, the solutions are varied and each person must find the one that works for her/him. Suggestions include gentle exercise, TaiChiChih and visual focus. Vision was also discussed. Some people experience blurry vision, especially when fatigued. It appears to be a fluctuating condition and, for most, rest seems to be the only solution.

Supplements are often a significant part of the treatment of ME/CFS and FM. Knowing what ones to take for a symptom, how much to take and which brands to purchase are difficult questions to answer. We suggest that you examine the treatment protocols of leading physicians and researchers such as Drs. Chaney, Podell, Natelson, Teitelbaum and others, AND then discuss your options with your physician. Supplements are not without side-effects and many could interact with medications or be dangerous to concurrent medical conditions. Supplements are an important part of the treatment of ME/CFS and FM. We caution you to use them safely and under medical supervision.

WEATHER – In the event of bad weather, we encourage you to check your email before leaving for Ridgewood. If it has been decided that a meeting will be canceled, an email will be sent via the yahogroups list. The “Y” will also be notified of the cancellation. The email posting also applies to a cancellation of the First Wednesday of the Month lunch gathering. This is an informal gathering, an opportunity for people to gather and chat with other members.

Social – First Wednesday of the Month Lunch

Wednesday February 4th

Lunch

at

The Seville Diner

289 Broadway

Westwood

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

Just show up.

In the News – Living with ME/CFS and FM

Barriers to healthcare utilization in fatiguing illness: a population-based study in Georgia

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Abstract

[Full article can be found at <http://www.biomedcentral.com/1472-6963/9/13>]

Background

The purpose of this study was to determine the prevalence of barriers to healthcare utilization in persons with fatiguing illness and describe its association with socio-demographics, the number of health conditions, and frequency of healthcare utilization. Furthermore, we sought to identify what types of barriers interfered with healthcare utilization and why they occurred.

Methods

In a cross-sectional population-based survey, 780 subjects, 112 of them with chronic fatigue syndrome (CFS), completed a healthcare utilization questionnaire. Text analysis was used to create the emerging themes from verbatim responses regarding barriers to healthcare utilization. Multiple logistic regression was performed to examine the association between barriers to healthcare utilization and other factors.

Results

Forty percent of subjects reported at least one barrier to healthcare utilization. Of 112 subjects with CFS, 55% reported at least one barrier to healthcare utilization. Fatiguing status, reported duration of fatigue, insurance, and BMI were significant risk factors for barriers to healthcare utilization. After adjusting for socio-demographics, medication use, the number of health problems, and frequency of healthcare utilization, fatiguing status remained significantly associated with barriers to healthcare utilization. Subjects with CFS were nearly 4 times more likely to forego needed healthcare during the preceding year than non-fatigued subjects while those with insufficient fatigue (ISF) were nearly 3 times more likely. Three domains emerged from text analysis on barriers to healthcare utilization: 1) accessibility; 2) knowledge-attitudes-beliefs (KABs); and, 3) healthcare system. CFS and reported duration of fatigue were significantly associated with each of these domains. Persons with CFS reported high levels of healthcare utilization barriers for each domain: accessibility (34%), healthcare system (25%), and KABs (19%). In further examination of barrier domains to healthcare utilization, compared to non-fatigued persons adjusted ORs for CFS having “accessibility”, “KAB” and “Healthcare System” barrier domains decreased by 40%, 30%, and 19%, respectively.

Conclusions

Barriers to healthcare utilization pose a significant problem in persons with fatiguing illnesses. Study results suggested two-fold implications: a symptom-targeted model focusing on

symptoms associated with fatigue; and an interactive model requiring efforts from patients and providers to improve interactions between them by reducing barriers in accessibility, KABs, and healthcare system.

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NJCFSA Notes

The Bergen ME/CFS/FM Support Group is a part of The New Jersey Chronic Fatigue Syndrome Association, Inc. It is an international recognized organization that plays a very active role in making ME/CFS known and helping those who have the illness. From time to time we bring you information about activities and fund raisers. We ask you to consider support these causes and we strongly urge you to join the NJCFSA. A membership form can be found at www.njcfsa.org. We also encourage those with Fibromyalgia to become members, as FM is of co-addressed with CFS. Here are some current initiatives.

• Tax Time

It is that time of year again. Our parent organization, NJCFSA announced that H&R Block will donate \$25 to the NJCFSA for each NEW client who uses the bottom portion of the attached form. See below. Please share this with friends and family.

If the flyer format has become jumbled, it can also be found in PDF format at the NJCFSA website <http://www.njcfsa.org>.

The NJCFSA and the Bergen ME/CFS/FM support group do not necessarily endorse this sponsor, but are very grateful for their commitment to charitable contributions.

• Marissa's Auction

Marissa's Auction – Please see the flyer included in this newsletter. Even if you cannot attend, we encourage you to consider purchasing a ticket or making a donation of items to be auctioned. The auction includes high end items and Marissa assembles baskets of smaller items for auction as well.

Next Meeting

The next meeting will be Sunday February 15th from 2-4 PM at the Ridgewood YMCA. Topic – to be announced.

This newsletter is intended for CFS & FM 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 leave a voice message at the NJCFSA HelpLine 888-835-3677 during business hours.

See attachments below

Marissa's 4th Annual Gift Auction

**The 2009 Gift Auction to benefit the NJCFSA
Saturday May 9, 2008**

at

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.

Marissa Newell is an NJCFSA Youth Trustee. She spends months gathering gifts and preparing for this annual event. She is an amazing fundraiser and the NJCFSA salutes her and her efforts



New Jersey Chronic Fatigue Syndrome Association, Inc

MEMBERSHIP & CHARITABLE CONTRIBUTION FORM

Annual Membership Dues: ___ New member ___ Renewal..... \$ 30.00

All membership dues go into the General Fund.

Additional Tax Deductible Contribution: ___ \$25 ___ \$50 ___ \$100 ___ other..... \$ _____

Apply my additional contribution to ___ General Fund ___ High School Scholarship
___ Research ___ Medical School Scholarship

- *The General Fund supports the daily activities of the organization.
*Become a Pillar of NJCFSA: Contribute \$100 or more to the General Fund.
*Contributions will be gratefully acknowledged in the NJCFSA newsletter unless requested otherwise.

Total Membership Fee and Charitable Contribution Enclosed..... \$ _____

(Please note: members who request reduced dues must return this renewal form to continue membership. Please consider that we need your membership dues to continue to provide ongoing services and benefits to our members. Fill in amount paid above. Please indicate why you request reduced dues on the line below.)

Member Information:

Please Circle One: PATIENT SUSPECTED PATIENT FAMILY FRIEND OTHER _____

New Member (or changes to a current member's) Information:

Name _____ Phone (____) _____

Address _____ County _____

City _____ State _____ Zip Code _____

Email _____

Are you a member of a local NJCFSA support group? If so, which county? _____

To join our Telephone Support Network so that you can speak with other members, please sign below.

Signature for Telephone Support Network.

Please see other side.

We need your help to keep NJCFSA running smoothly. Listed below are some volunteer opportunities. These can be one time commitments or longer if you are able to help more. Please check all the ways you would be interested in helping us.

_____ Board member of NJCFSA

_____ Coordinate Volunteers

_____ Conference Coordinator

_____ Conference Committee Member

_____ Coordinate Newsletter

_____ Write for newsletter

_____ Help with mailings

_____ Post posters and notices in your community

_____ Advertise our conferences and other events

_____ Ideas for fundraisers

_____ Help with fundraisers

_____ Find corporate sponsors for our conferences and other programs

_____ Grant writing

_____ Lead a support group in your area

_____ Begin an informal phone support group

_____ Other: Please explain _____

**Please send form and dues to:
NJCFSA, Inc. P.O. Box 477, Florham Park, NJ 07932
Phone 888-835-3677 – <http://njcfsa.org>**