



Bergen ME/CFS-FM Support Group Newsletter

Meeting Report

The featured speaker for this meeting was Dennis Oehm of H&R Block of Ridgewood, who addressed deductions and disabilities. Mr. Oehm prefaced his presentations by stating that talks of this type are offered by H&R Block – not as a sales pitch but as a service to the community. He provided attendees with several publications about disability deductions. These can be found at <http://www.irs.gov/pub/irs-pdf/p907.pdf> (this is a PDF file. It can be opened if you have Adobe Acrobat Reader installed. If you do not have Adobe, but and wish to read about these disabilities go to <http://search.irs.gov/web/query.html?col=allirs&charset=utf-8&qp=&qq=-Wct%3A%22Internal+Revenue+Manual%22&qc=&qm=0&rf=0&oq=&qt=publication+907> .

Mr. Oehm also answered many questions from our members. The basic formula is that a percentage of everything connected with healthcare - that is not covered by insurance - is probably eligible as a deduction, if the total amount exceeds the standard medical deduction. Included in those possible deductions are co-pays, long term care premiums, lab fees, physical therapy, health aids, transportation costs, tolls, and parking. Exercise programs might be deductible if they are ordered by a physician. Mr. Oehm suggested reading the IRS information and discussing your options with a tax preparer.

New Fact Sheet. The NJCFSA has added a fourth fact sheet – for Friends, Family and Caregivers. This complements the previous three: General Fact Sheet, Children & Adolescents, and Women & Pregnancy. The new fact sheet has been included at the end of this newsletter.

WEATHER – In the event of bad weather, we encourage you to check your email before leaving for Ridgewood. If it has been decide that a meeting will be canceled, an email will be sent via the yahoogroups 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 March 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. It is an additional alternate way to connect with others who are living with ME/CFS/FM.

In the News - ME/CFS

International Press Release:

Noted Scientist Reports Real Progress in ME/CFS Research

Reported February 23, 2009

by Dan Moricoli for www.me-cfsCommunity.com and www.cfsknowledgeCenter.com

"A biomarker for ME/CFS may be less than two years away." According to Dr. Nancy Klimas one of the pre-

eminent, research scientists in the world on ME/CFS (also known as chronic fatigue syndrome or myalgic encephalomyelitis).

"We are closing in on being able to identify the root causes of a disease which afflicts millions of people around the world. One that is poorly understood and treated by the medical community.

Understand," she went on to say, the excitement rising in her voice, "that physicians practice, or at least strive to practice, evidence based medicine. The demands on a physician are so overwhelming that they are virtually forced to concentrate their efforts only on those medical conditions which can be clearly and objectively identified.

That is simply not yet the case with ME/CFS." She added with emphasis.

"Just think for a moment, what it would mean to the millions of sufferers of ME/CFS if any doctor could run a test which would clearly, indisputably identify the patient as having the disease, EVERYTHING CHANGES." Again, adding emphasis to her words as she spoke with great passion and concern.

"Drug companies will add untold millions in research in their rush to develop medicines to treat the disease. In short order, local physicians will finally be able to begin to identify, understand and treat their patients properly. No longer will those afflicted be dismissed by the medical community and, all too often, by their own family and friends as having that 'yuppie thing'."

Dr. Klimas shifted in her chair and with the precision and determination of a research scientist in both her eyes and voice went on to say. *"There are at least three, perhaps even seven, sub-groups of what we call ME/CFS that are currently under intense research focus. They may be thought of as three to seven different conditions with closely related symptoms. As we identify and conduct more focused research on each of the sub-groups even more bio-markers will be identified and treatments developed over time.*

That we are on the brink of identifying biomarkers for at least a few of these subgroups is very exciting. Particularly if one considers all that will then come from what is now so close at hand" she added.

Dr. Klimas made these remarks to me in our conversation Friday, February 20th in her office at the University of Miami. I had asked to see Dr. Klimas to talk about current ME/CFS research initiatives so that I might update the patient community through the websites www.cfsKnowledgeCenter.com and www.me-cfsCommunity.com for which I write.

As an ME/CFS patient, and someone who, at least thinks of himself as being fairly active and somewhat knowledgeable in the ME/CFS community, I simply had no idea how close at hand treatment might prove to be for us. I was stunned. Regaining my composure and with all the businesslike demeanor I could muster, I asked "What's next?"

"Money." She said simply. *"I would guess about \$10million over the next five years, maybe a little longer for clearly focused international research. ME/CFS is worldwide problem that afflicts at least 28,000,000 people, perhaps many more than that.*

Japan and Spain both have great research underway in their very different national approaches to the disease. In the UK, Jonathan Kerr and others are also doing particularly noteworthy research. Here in the United States, there is other fine work underway as well but we, too, have our own idiosyncrasies with respect to research funding and results evaluation.

The disease is so widespread, however, that while nationalized approaches are without question valuable, a clearly focused international approach will clearly and dramatically speed up the process and the resulting benefits for those afflicted."

My meeting with Dr. Klimas, made it particularly clear, and deeply personal to me, why the newly introduced IACFS/ME Research Fund is so vitally important to those of us who suffer from this dreaded disease.

Interestingly, Dr. Klimas who is the current president of the International Association for CFS/ME (IACFS/ME) did not mention the new fund once during the 90 minutes she spent with me. She was clearly not trying to "sell" me or anyone else on the fund. This was simply a deeply concerned and compassionate physician and research scientist speaking about that which she has devoted her life to.

If you are concerned about having a treatment for ME/CFS, let alone having access to a doctor who is willing to treat you, instead of dismissing your symptoms with a raise eyebrow, you owe it to yourself to add what you can to the IACFS/ME Research Fund. Whether it's \$5 or \$20 or \$500 or more, please do it. Please do it now. For more information about the IACFS/ME Research Fund or to make a donation, click [HERE](#). For more information about their work, click on [IACFS/ME](#). To join the IACFS/ME, click [HERE](#).

The **9th International IACFS/ME Research and Clinical Conference** is scheduled for March 12-15, 2009 at the Peppermill Resort in Reno, Nevada. A patient conference is included in the program in which patients will hear directly from such noted scientists as Nancy Klimas, M.D., Dan Peterson, M.D., Anthony L. Komaroff, M.D., Fred Friedberg, Ph.D., Lenard Jason, Ph.D., Hirohito Kuratsune, M.D., Kenneth Friedman, Ph.D. and Gudrun Lange, Ph.D. For a complete agenda click [HERE](#).

For more information about the *ME-CFS* **Community** website, click [HERE](#).

For more information about www.cfsKnowledgeCenter.com, click [HERE](#).

[NJCFSA Notes](#)

FM Community Responds to AP Article

<http://www.fmaware.org/site/News2?page=NewsArticle&id=8481>

The Associated Press article by Matthew Perrone (February 8, 2009, "Drugmakers' push boosts 'murky' ailment) has drawn several comments. [Click here](#) to read the article.

NFA's response to the Associated Press.

Focus on the Facts

The recent Associated Press story on fibromyalgia hardly qualifies as news; it merely regurgitates the same arguments that have been published in the past and offers the opinions of the same two men who have built careers out of drawing attention away from the hundreds of scientists who continue to make amazing scientific strides toward understanding the underlying cause(s) and pathophysiology of what fibromyalgia patients experience. By perpetuating this message, the article implies that it is more acceptable to debate names or labels for this "set of symptoms" and to point fingers at the usual "villains" (i.e.: pharma and the nonprofits who accept money from them), than to focus on the millions of desperate patients who deserve to have a voice in the discussion. The fact is that credible medical institutions and organizations recognize fibromyalgia as a life-altering disease; the fact is that patients who suffer with FM depend on the medical system (including pharmaceutical companies) to help them inform the public that this is a very real illness and that they need treatments, including pharmaceutical agents, to help them get through each day—and to look forward to some sort of quality of life in the future.

This article misinforms readers in a way that undermines and victimizes innocent people. By telling only selective parts of the story the author is perpetuating misperceptions and making it difficult, if not impossible, for readers to grasp what is truly important: that we need to stop debating and pointing fingers and start asking why it is perceived as acceptable to stigmatize a patient population just because medical research hasn't yet provided us with all the information needed to understand that particular illness. Every illness seems to go through a stage of having to prove its legitimacy, but why

should the patients be suspect during that phase of research?

Why would AP print information that is simply not true—i.e.: people with fibromyalgia are “more likely to have a history of mental illness and are economically disadvantaged?” That is totally false, as is the writer’s statement that the National Fibromyalgia Research Association received pharma money to fund Dr. Clauw’s functional MRI study. The money for all of the NFRA’s funded research came from the founder (the husband of a fibromyalgia patient), general donations, and revenue generated from a nonprofit bingo game. (Yes, the FM community has had to rely on bingo games to fund our research!)

How can we allow the system to fail millions of people whose only “fault” is to have developed a devastating illness? Along with the rest of the fibromyalgia patient community, I look forward to the day when society (including the medical community, the media, and our government agencies) accepts the responsibility of treating fibromyalgia patients like any other group of chronically ill patients; when it is a given that fibromyalgia will be further studied, that treatments will be developed and made accessible to patients, that the media presents the facts rather than perpetuating threadbare controversies.

Now *that* would be news worth printing.

Lynne Matallana

President, National Fibromyalgia Association

Next Meeting

The next meeting will be Sunday March 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.

Chronic Fatigue Syndrome (ME/CFS)

Information for Family, Friends and Caregivers

Lorraine Steefel, RN, DNP

Chronic Fatigue Syndrome (CFS) is a serious, complex and often disabling illness, which affects at least one million American men, women and children of all races and economic backgrounds. Four times as many women as men are affected. The illness is also called Myalgic Encephalomyelitis (ME) and Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) and it is found worldwide. The acronym ME/CFS is now increasingly being used.

Many people with ME/CFS are very ill and need a lot of help and support from family and friends. The value of caregivers support is immense and should not be underestimated. Most caregivers, are wholehearted in their wish to help, but to provide effective assistance, they also need to know about the illness and how it has affected their friend or family member. When the patient is too ill to act for her/himself, caregivers have an important role acting as advocates and facilitating communication between the patient and healthcare provider.

What is ME/CFS?

Profound fatigue lasting at least six months in adults, or three months in children, is a major component of the illness. This debilitating fatigue is accompanied by a wide array other symptoms. ME/CFS symptoms are made worse by physical and mental activity, are not relieved by rest and result in a substantial loss of ability to function. The pattern and number of symptoms varies among patients, and symptoms may change in severity from day to day, or hour to hour.

ME/CFS symptoms include:

After exertion, malaise, muscle weakness and other symptoms worsen. Recovery is delayed 24 hours or more

Unrefreshing sleep, daytime hypersomnia (excessive sleep) and/or nighttime insomnia

Widespread migratory muscle or joint pain (without swelling) or headaches (a new type or more severe)

Neuro-cognitive symptoms include impaired short-term memory, difficulty in concentration, difficulty finding words and/or numbers, inability to multitask, disturbed balance, hypersensitivity to noise, light or emotional overload.

Autonomic symptoms include facial pallor, dizziness, palpitations, inability to stand up for any length of time (orthostatic intolerance), urinary frequency and bowel

symptoms (irritable bowel syndrome.)

Neuro-endocrine symptoms include sweating, feeling feverish, intolerance to heat and cold, low body temperature, abnormal appetite, symptoms that worsen with stress.

Immune manifestations include tender lymph nodes, recurrent sore throats and flu-like symptoms, or a new sensitivity to food, medications or chemicals.

The illness usually starts suddenly with fever and flu-like symptoms, but the onset can be gradual. Some patients improve slowly and can return to work part or full time; others have relapses and remissions; some remain housebound; and some are bed-bound. Up to 15% of patients recover within 10 years.

Because there is no diagnostic test for ME/CFS, the diagnosis depends upon the patient's symptoms meeting the criteria of one of several case definitions. The 1994 International Case Definition is the most commonly used. However, it excludes some patients with genuine ME/CFS who do not exactly fit the criteria. The 2003 Canadian Clinical Case Definition was produced to overcome this problem. A Pediatric Case Definition is available for diagnosing children and adolescents. All definitions require ruling out other fatiguing illnesses before declaring it ME/CFS.

Although there is no cure for the illness, medication can be useful in the relief of individual symptoms. Illness management is aimed at helping patients adapt their lifestyle to their existing capabilities (pacing).

How ME/CFS Affects patients

ME/CFS affects every aspect of the patient's life and her/his quality of life is often very poor. Once-active adults find themselves needing to rest instead of caring for others. They are forced by the illness to spend time away from their responsibilities at work, at home, or at school (for children). Functional impairment may induce feelings of anger, sadness or guilt. Patients frequently focus on their symptoms, their treatment and their hopes for recovery. ME/CFS takes a significant toll on families. Some spouses may be unable to cope with the illness.

Financial concerns can create serious personal hurdles for patients with ME/CFS. Inability to work, leading to unemployment, together with ongoing financial expenditures, force the patient to apply for disability benefits. This process is difficult, time consuming and saps energy.

Inability to function or malaise may cause the patient to avoid making advance plans, cancel planned activities and become socially withdrawn.

ME/CFS patients typically do not look ill, so friends, family, and some healthcare providers may think that they are malingering. Consequently, many patients experience unkind reactions from those who think the illness is “all in their heads” and it may lead to a lack of confidence or self-esteem.

Obtaining suitable healthcare is difficult, even if the patient has not lost her/his medical insurance. The illness is not part of any medical school curriculum. Many healthcare providers are ignorant about ME/CFS, or deny it exists. It may be difficult to obtain a diagnosis or proper treatment for symptoms.

A prime diagnostic feature of this illness is a worsening of symptoms after exertion. Well-meaning friends or uninformed healthcare providers may encourage a patient to do more than she/he is able. This can cause a relapse of the illness. Patients need to learn to pace themselves.

How Caregivers Can Help Support and Communication

- The top priority for caregivers is to offer physical and emotional support. Caregivers should keep an open line of communication with patients, by being non-judgmental toward both patients and the professionals with whom they must collaborate.

- Validate the patient, confirming your belief that they have a serious illness, even if a healthcare provider shows doubt. (Then, offer to help find a supportive healthcare provider.)

Ask the patient, what they need and how you can help. Listen to the patient rather than providing suggestions on how to “fix” things.

- Offer support and be understanding when she/he cancels plans due to illness or fatigue.

- Offer positive responses such as, “I’m sorry you’re feeling so bad” or “You’re handling things so well,” or “I know this is difficult for you.”

- Avoid comments such as, “You can beat this thing, if you try hard.” Avoid negative comparisons such as, “You walked for a longer time yesterday” or “You used to have such energy.”

Education

Caregivers should learn about ME/CFS and how it affects the patient. Learn where to find valid information

about the illness and where to turn when help is needed. Information about ME/CFS can be found at The New Jersey Chronic Fatigue Syndrome Association (NJCFSA) website, www.njcfsa.org, or Help Line, **888-835-3677**. A large library of books and periodicals about ME/CFS is also available to members. Caregivers are welcomed at local support group meetings and NJCFSA conferences. For information about these, contact the NJCFSA.

Healthcare

ME/CFS patients may need help navigating the healthcare system. Finding a healthcare provider who is able to diagnose and manage this devastating and puzzling illness can be difficult. The NJCFSA maintains a **list of ME/CFS knowledgeable healthcare providers**. Some patients may be unable to drive and may need someone to attend medical appointments with them. The caregiver can help the patient to report her/his most pressing problems, ask appropriate questions and take notes about the doctor’s recommendations and comments. ME/CFS treatment is symptom-based and supportive.

Practical Things You Can Do

Notice what activities of daily living the patient has difficulty completing, such as getting dressed or balancing the checkbook. Offer specific help, such as laying out clothing, assistance with organizing bills, or computing bank balances. Suggest that the patient keep needed items, such as keys, in a specific place. Write down directions or instructions.

Things You Can Do for Yourself as Caregiver

Caregivers need to know their own limitations and how to care for themselves. They also need support and “down time.” Caregivers can sometimes feel angry or guilty and may need to talk with a friend or another support person. It’s a good idea to set reasonable expectations for the care you are able to offer. Let the patient know when you need a break. Continue to enjoy your life, friends and activities. Give yourself credit for what you do for the patient.

For More Information on ME/CFS

Visit www.njcfsa.org. Call **888-835-3677**.

E-mail: njcfsa@njcfsa.org

References

Berne, K. For those who care fact sheet. www.cfids.org

What is CFS? www.njcfsa.org

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