



## Bergen ME/ CFS-FM Support Group Newsletter

### Meeting

How exciting it was to see so many people at the February meeting. A video segment from the NJCFSA 2008 Fall Conference was shown. The presenter, Patricia Fennell is a social worker who discussed copying with chronic illness. The remainder of the meeting was open discussion on a hot topic related to the talk. The chat wandered from the topic but was obviously where this group needed to go. There was a lengthy discussion about purchasing supplements - especially which sources were the cheapest and the best. For all of you, we have included information that we hope will help you make wise choices.

[http://www.supplementquality.com/testing/Quality\\_seals.html](http://www.supplementquality.com/testing/Quality_seals.html)

The above site lists 4 quality seals that can be found on some supplements. Price does not guarantee quality. It also answers the following questions:

*What do these quality seals mean?*

*What do these criteria mean? Including: identity and potency, purity, bioavailability, consistency and good manufacturing practices (GMPs.)*

Please go to the site for a full text which includes these source: ConsumerLab website, Natural Products Association (NPA, formerly NNFA) website, NSF International website and US Pharmacopoeia (USP) website. ■

<http://www.usp.org/audiences/consumers>

This second site outlines the role of the US Pharmacopoeia (USP) in bringing you safe reliable products.

<http://dietary-supplements.info.nih.gov/factsheets/dietarysupplements.asp>

Here you will find the answers to the following questions:

What is a dietary supplement?

What is a new dietary ingredient?

Are dietary supplements different from foods and drugs?

What claims can manufacturers make for dietary supplements and drugs?

How does FDA regulate dietary supplements?

What information is required on a dietary supplement label?

Does a label indicate the quality of a dietary supplement product?

Are dietary supplements standardized?

What methods are used to evaluate the health benefits and safety of a dietary supplement?

### In the News

We have been trying to find answers for those who are confused by the recent changes in NJ disability Medicare drug plans. Here are a few sites you might find helpful. If we discover more information, we will pass it along to you.

<http://www.medicareolutions.com/?sourceId=1&mediumId=4&campaign=MEDICARE>FL>Geo&adGroup=Medicare>Part%20D&keyword=medicare%20d&matchType=Broad&temp1=1&gclid=CPrT7fmziaACF>

[Otx5Qodjkyxmg](http://Otx5Qodjkyxmg)  
<http://mymedicare.gov>  
[www.rx4nj.org](http://www.rx4nj.org)

## In the News – Part 2



[http://news.yahoo.com/s/ap/us\\_gulf\\_war\\_illness](http://news.yahoo.com/s/ap/us_gulf_war_illness)

### **VA to reopen Gulf War vets' files**

By KIMBERLY HEFLING, Associated Press Writer Fri Feb 26, 8:38 am ET

WASHINGTON – The Veterans Affairs Department says it will take a second look at the disability claims of what could be thousands of Gulf War veterans suffering from illnesses they blame on their war service, the first step toward potentially compensating them nearly two decades after the war ended.

VA Secretary Eric Shinseki said the decision is part of a "fresh, bold look" his department is taking to help veterans who have what's commonly called "Gulf War illness" and have long felt the government did little to help them. The VA says it also plans to improve training for medical staff who work with Gulf War vets, to make sure they do not simply tell vets that their symptoms are imaginary — as has happened to many over the years.

"I'm hoping they'll be enthused by the fact that this ... challenges all the assumptions that have been there for 20 years," Shinseki told The Associated Press in an interview.

The changes reflect a significant shift in how the VA may ultimately care for some 700,000 veterans who served in the Gulf War. They also could improve the way the department handles war-related illnesses suffered by future veterans, because Shinseki said he wants standards put in place that don't leave veterans waiting decades for answers to what ails them.

Steve Robertson, legislative director of the American Legion and a Gulf War veteran who has struggled with his own health issues such as joint problems and chronic fatigue, said Friday the decision is welcome news.

"I can assure that there are Gulf War veterans who have been fighting this issue since 1991-92," Robertson said. "The ones I've talked to are very, very upset that they've had to fight this battle."

Robertson said many veterans couldn't work because of health problems, but couldn't get medical help from the government because they couldn't prove their illnesses stemmed from their war service.

"If you had an invisible wound it was kind of like come back when you have hard evidence that you got it in the theater of operation," Robertson said.

The decision comes four months after Shinseki opened the door for as many as 200,000 Vietnam veterans to receive service-related compensation for three illnesses stemming from exposure to the Agent Orange herbicide. About 175,000 to 210,000 Gulf War veterans have come down with a pattern of symptoms that include rashes, joint and muscle pain, sleep issues and gastrointestinal problems, according to a 2008 congressionally mandated committee that based the estimate on earlier studies.

But what exactly caused the symptoms has long been unanswered. Independent scientists have pointed to pesticide and pyridostigmine bromide pills, given to protect troops from nerve agents, as probable culprits. The 2008 report noted that since 1994, \$340 million has been spent on government research into the illness, but little has focused on treatments.

Last week, Shinseki and Sen. Jay Rockefeller, D-W.Va., a member of the Senate Veterans' Affairs committee, met privately in Charleston, W.Va., with several Gulf War veterans. In an interview after the meeting, Rockefeller told the AP that Shinseki's background as a former Army chief of staff made the changes possible. He said either the military has been reluctant over the years to release paperwork related to the war or kept poor records about exposures in the war zone, which made it harder for the veterans to prove they needed help.

"The paperwork isn't very accurate, but the pain is very real," Rockefeller said.

Shinseki has publicly wondered why today there are still so many unanswered questions about Gulf War illness, as stricken veterans' conditions have only worsened with age.

Last fall, he appointed a task force led by his chief of staff, John Gingrich, a retired Army colonel who commanded a field artillery battalion in the 1991 war, to review benefits and care for Gulf War veterans. The changes stem from the task force's work.

Gingrich said he feels a personal stake because some of his own men who were healthy during the war are dealing with these health problems. Gingrich said the VA isn't giving a new benefit to Gulf War veterans, just making sure the claims they submitted were done correctly.

We're talking about a culture change, that we don't have a single clinician or benefits person saying 'you really don't have Gulf War illness, this is only imaginary' or 'you're really not sick,'" Gingrich said.

A law enacted in 1994 allows the VA to pay compensation to Gulf War veterans with certain chronic disabilities from illnesses the VA could not diagnosis. More than 3,400 Gulf War have qualified for benefits under this c  
The VA says it plans to review how regulations were written to ensure the veterans received the compensation they were entitled to under the law. The VA would then give veterans the opportunity to have a rejected claim reconsidered.

The VA doesn't have an estimate of the number of veterans who may be affected, but it could be in the thousands.

Of those who deployed in the Gulf War, 300,000 submitted claims, according to the VA. About 14 percent were rejected, while the rest received compensation for at least one condition.

---

On the Net:

Veterans Administration: <http://www.va.gov>

## **Coming Events!**

### **Watch for details!**

- The NJCFSA Conference is set for Sunday October 17, 2010. The program line-up will be announced in the near future. Mark your calendar. It will be a great day.
- Watch for the announcement of an additional special NJCFSA event this spring. Information will be sent as soon as the details are completed.

## **Next Meeting**

The next meeting will be held on Sunday March 21<sup>st</sup>. Agenda – **Some Times You Just Have to Laugh.** This video segment is from the Oct. 2006 NJCFSA conference. Current trustee, Trisha Steefel shared her humorous account of what it was like to be an adolescent CFS and Fibromyalgia. She was an adult when she presented it and many of you will relate to her experiences.

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 [pcl.njcfesa@gmail.net](mailto:pcl.njcfesa@gmail.net), Nancy Visocki at [ngv.njcfesa@verizon.net](mailto:ngv.njcfesa@verizon.net), Judy Machacek at [judymachacek@msn.com](mailto:judymachacek@msn.com) or leave a voice message at the NJCFSA HelpLine 888-835-3677 during business hours.

**WEATHER or Emergency** – *In the event of bad weather, or other emergency, we encourage you to check your email before leaving for Englewood. If it has been decide that a meeting will be canceled, an email will be sent via the yahoogroups list. The Hospital will also be notified of the cancellation. The email posting also applies to a cancellation of the First Wednesday of the Month luncheon which is an informal gathering, an opportunity for people to meet and chat with*

If the following two pages: New Jersey Chronic Fatigue Syndrome Association, Inc.: Chronic Fatigue Syndrome (ME/CFS) Information for Family, Friends and Caregivers becomes jumbled in transit and if you want a copy, please email us and I will send you a copy as a PDF attachment

**New Jersey Chronic Fatigue Syndrome Association, Inc.**  
**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](http://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](http://www.njcfsa.org). Call **888-835-3677**.

E-mail: [njcfsa@njcfsa.org](mailto:njcfsa@njcfsa.org)

**References** Berne, K. For those who care fact sheet.

[www.cfids.org](http://www.cfids.org) . What is CFS? [www.njcfsa.org](http://www.njcfsa.org)