



Bergen ME/ CFS-FM Support Group Newsletter

Meeting Report

The support group met in the new location. For those of you who attended the spring Lunch and Learn, it is the room that was used that day. Despite Nancy's hard work to have it run smoothly, there were a few snags. But, the EHMC staff was helpful and everything was eventually straightened out. The Dr. Susan Levine segment of the NJCFSA Fall conference was played and acclaimed by those in attendance. The hot topics portion was very quiet this month – partly because it took place while the staff was trying to get the video running. Let's face it, technology is always more fascinating.

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Host: Kenneth Friedman, PhD Moderator: Malcolm Schwartz, MD

Speakers: Judy Mikovits, PhD/James Oleske, MD, MPH/Susan Levine, MD/Barbara Comerford, Esq.

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We also the movie "Invisible" (\$20.) This documentary about living with ME/CFS was made by Rik Carlson, Michael Thurston and the Vermont CFIDS Association. NJCFSA has a few copies to sell. Please send check payable to: NJCFSA to the address above.

Be sure to indicate which video or videos you wish to purchase. Please include a phone number in case there is a question about your order.

On behalf of the leadership team, may your holidays be happy and may the new year find you in good health.

ME/CFS in the News



Chronic Fatigue Syndrome Patients Grow Weary of Doubt - Doctors, Patients Roiled By CDC Study Linking Personality Disorders to Chronic Fatigue Syndrome

<http://abcnews.go.com/Health/MindMoodResourceCenter/chronic-fatigue-syndrome-link-personality->

[disorders/story?id=12102316&page=3](#)

Teresa Serice tried to lift her arms. It was her daughter's wedding day, and she needed to get into her mother-of-the-bride dress. She struggled to slip it on as her husband offered to help. No, she told him. She'd do it herself. And after several minutes, she found the physical strength to put on the dress.

In July of 2007, Serice's life came to a standstill when she began suffering from a degree of fatigue she had never before experienced. A year later, she was diagnosed with chronic fatigue syndrome, or CFS, a condition that caused basic tasks like laundry and blow drying her hair to leave her exhausted and breathless. "Walking from my bedroom to my kitchen now can feel like I'm trying to cross the Sahara Desert," said Serice, a 49-year-old resident of Kaiser, Ore.

CFS is a condition associated with prolonged and severe fatigue that is not improved through rest and sleep. Many CFS patients also have brain fog symptoms, described as bouts of unusually poor mental function that includes confusion, forgetfulness and difficulty concentrating. According to the Centers for Disease Control and Prevention, the causes of CFS are largely unknown, but some possible triggers include infectious agents, immunological dysfunction and nutritional deficiency. The condition has long been surrounded by controversy. For years, many doctors wouldn't recognize chronic fatigue syndrome as a legitimate disorder. Many CFS patients say they have visited doctors who are totally unaware of the illness. When tested, patients' lab work often comes back clear, and because of this, some doctors have argued that the condition is psychological, not physiological.

In a study conducted by the Centers for Disease Control and Prevention and Emory University School of Medicine, researchers found that CFS was associated with an increased prevalence of personality disorders. Authors also said that personality may be a risk factor for CFS and may contribute to the maintenance of the illness.

"I think that's the biggest bunch of horse hoey I've ever heard," said Serice, who has a master's degree in business administration. "It's insulting. I spent my time, money, and education to get to work at an executive level and it's all been knocked out from under me because I'm tired?"

But Dr. Elizabeth R. Unger, acting chief of CDC's Chronic Viral Diseases Branch and spokesperson for the study, said that personality disorders may not cause CFS but rather, act as a secondary symptom of any chronic or severe disease. "Other studies have found personality disorders were associated with fatigue and depression, as well as with chronic fatigue syndrome," said Unger. "The objectives of this study were to follow up on previous personality research as well as to describe the prevalence of personality disorders in people with CFS.

CFS Sufferers Struggle With 'All in the Head' Rationale

Twenty-seven-year-old Erin Adams has suffered from CFS for nine years. She missed her entire senior year of high school when she first fell ill to the disease. "They're focusing on the wrong problem by saying it's all in your head," said Adams, a part-time teacher who lives in Lake City, Fla. "Believe me, if it was all in my head, I'd be so happy. Send me to a shrink and give me some medicine." Adams said she wishes it was so black and white. It's hard to predict when she'll be feeling well enough to venture outside, she said, or when she'll feel so exhausted that walking to her own bathroom will cause her heart palpitations and weakness.

Because so many doctors told Heather Sparrow, a 24-year-old resident of Farmington, Maine, that nothing was wrong with her, self-doubt began to set in. "I went through five different doctors and it took ruling out everything," said Sparrow. "It got to a point of thinking, 'OK, is this my head?'" Desperate for answers, Sparrow actually went to a therapist to find out if the symptoms were her actually "in her head." The therapist told her she was fine, but her symptoms worsened. "I knew that a 24-year-old shouldn't feel like a 94-year old," she said. "I felt really alone. No one knew what I was feeling," she said.

Study Logistics Leave Some Doctors With Questions

In the study, published in the August issue of journal of Psychotherapy and Psychosomatics, study authors examined more than 500 patients from Georgia. More than 100 participants had been diagnosed with CFS, 264 participants had unexplained fatigue without CFS and another 124 healthy participants made up the control group.

Investigators administered the Personality Diagnostic Questionnaire, a survey used by health professionals to screen clients for various personality disorders. Study authors said that 29 percent of participants with CFS had at least one personality disorder, compared with 28 percent of the non-CFS patients and 7 percent of the control group. "A lot of people cried foul when this study came out, and since then, there has been rigorous debate," said Dr. Nancy Klimas, a professor of medicine, psychology, microbiology and immunology at the University of Miami Miller School of Medicine. "My reaction from my own clinical experience is: no, I don't believe that. My patients tend not to have those [personality] issues." Klimas explained that extensive scientific research shows that CFS is similar to an autoimmune disorder. "It's like we're getting slammed back to the 1980s with this article talking about personality disorders and disregarding all the scientific research that has taken place since then," continued Klimas.

Dr. Anthony Komaroff, the Simcox-Clifford-Higby professor of medicine at Harvard Medical School and editor-in-chief of Harvard Health Publications, said CFS first gain substantial attention in the mid-1980s. Komaroff said many doctors thought CFS to be a psychiatric condition. "It was a reasonable possibility, but over the course of 25 years, there are literally thousands of peer-reviewed papers showing things you can measure in patients that are different from healthy people," said Komaroff. "There is abundant evidence showing that there are objective things to measure that people aren't just imagining being there. There is an underlying biological process." "I feel bad about this study because these poor patients get nothing but attitude, they're patronized and have a poor standard of care," said Klimas. "It's just not right. They're terribly ill and they deserve better than that. "

Psychiatric Disorders as a Secondary Symptom of CFS

Several doctors did agree that a psychiatric disorder is often seen as a secondary symptom of CFS and other chronic diseases. Komaroff said it's natural for people to develop anxiety and depression after getting sick with a chronic disease, and it shouldn't be confused with a risk factor. "Having an illness suddenly develop out of the blue, where doctors aren't sure what it is and there aren't standard tests for it will have a psychological effect on the person," said Komaroff. "It would on me."

Dr. Ellen Slawsby, director of pain services at Benson Henry Institute for Mind Body Medicine at Massachusetts General Hospital, said that she does not see as high of a prevalence of personality

disorder in her clinic as was found in the study population. "The depression that I have observed seems to be secondary to the illness setting," said Slawsby. "Many folks are told their fatigue and pain is all in their head, but I always go with the basis that there is something there." Unger points out that this could be the case in the study's CFS patients. "It's not clear whether any personality features identified in people with CFS in this study are a result of having CFS or if instead they are a risk factor for developing CFS," said Unger.

And for Sparrow, who was in her 20s with "the world at her feet" when she suddenly became ill, depression came soon after the diagnosis. "I'm on depressive medication because the illness made me so depressed," said Sparrow. "I don't understand when people say that this is all in my head. Why, when I was 24 years old with the best job I could ask for, would I give it up to be at home alone in my bed?"

Lifelong Enduring

Penny Cowan, executive director and founder of the [American Chronic Pain Association](#), said that it's tough road for chronic fatigue patients because there is no magic pill that will treat the disease and make it all go away. "CFS has gotten its share of bashing because people don't always believe it," said Cowen, who has suffered from chronic pain for more than 30 years and started the association as a resource for people who share her illness. "There is no 'aha' moment for treating the disease." "But this is something we have to learn to live with," she continued. "And they aren't able to tell us how to do that."

Making the most of the Holidays

Surviving the Holidays

By Karen Lee Richards

Editor's Note: When she wrote this article, Karen Lee Richards was Vice President of the National Fibromyalgia Association and Executive Editor of its magazine, Fibromyalgia AWARE. The article is reprinted from the Sept.-Dec. 2002 issue of the magazine, with permission of NFA.

Does the thought of another holiday season fill you with joyful anticipation or overwhelm you with fear and dread? The average person considers the holidays at least somewhat stressful. For people with fibromyalgia, who are already struggling to cope with daily life in general, the added demands and stresses of the holidays can trigger a flare of fibromyalgia symptoms. While you may not be able to totally avoid all stress, you can reduce your stress level significantly by giving yourself a G.I.F.T.

G - Guilt Must Go

Guilt is born when you fail to live up to your own expectations for yourself. Year after year you are bombarded with a "magical mythical model" of the idyllic holiday scene - complete with family, friends, food and festivities, encompassed in a spirit of peace and goodwill for all. If this is the holiday image you are trying to achieve, it is time for a reality check. The fact is, you have a chronic pain illness, which limits what and how much you can do. It's time to stop blaming yourself because you can't provide the elaborate holiday festivities you once did or because you can't do everything you think your family expects you to do. It's time to remember what the holidays are really about - expressing your love and thankfulness for family and friends. There are many ways to express those feelings without damaging your body in the process.

Decide right now that you will refuse to accept any feelings of guilt because of what you cannot do. Instead, focus your attention on what you can do. Then gather that old guilt up into a big ball, kick it out, and lock the door behind it!

I - Importance Rules

Do not let the holiday season descend upon you like a heavy weight. Decide which aspects of the holidays are most important to you and your immediate family. Focus on accomplishing the most important things and let everything else go. (If spending quality time together visiting is more important than a huge home-cooked meal, have your holiday dinner at a restaurant so you can relax and enjoy each other's company.)

Once you have decided what is most important to you for the holidays, share this with your immediate family. Then ask each family member what is most important to them (an elaborately decorated house, lots of baked goodies on hand, a big home-cooked dinner, visiting with other relatives, etc.). Family traditions are important but, just as families grow and change, some traditions may have to change as well. Hold on to the traditions and rituals that are most important to your family, but understand that it may be time for some traditions to change. Work together to come up with a compromise that everyone can live with. Ask each person in the family to take responsibility for some part of the holiday plans. Knowing ahead of time what the priorities and plans are will avoid disappointment and hurt feelings later.

F - Family Matters

During the holiday season, extended families come together, often traveling great distances. While it may be wonderful to visit with relatives not often seen, you need to plan ahead to avoid being physically drained by what should be an enjoyable experience. Whether they come to your home or you go to theirs, talk to them ahead of time and explain that you have a chronic illness which limits your activity and requires you to rest at regular intervals. Then, when you decline an invitation to go sightseeing or politely excuse yourself to go take a nap, you do not have to explain or feel guilty.

Keep in mind that your first responsibility is to yourself and your immediate family. If you are not feeling up to a large family gathering this year, simply explain that, as much as you would love to see everyone, your health will not allow you to participate this year.

Good communication with your family is a key to a happy holiday season. However, sometimes when we are not feeling well our attempts at communication may sound more like whining or complaining. Try to speak in a calm, logical, factual manner as you make plans or explain your limitations to family and friends. Be aware that some people may not understand at first but, if you calmly stand your ground, most will eventually come around.

T - Think ahead

A large portion of holiday stress comes from the last-minute rush to get everything done. Begin to plan your holiday season at least two months in advance. Put your plans on paper so that they are not lost in an unexpected attack of "fibro-fog." Make a gift list, write out menus and formulate a "to do" agenda. The next step is to simplify and delegate. Look at each item on your list and ask yourself, "Is this really important to me and/or my family?" If not, take it off the list. If it meets the importance criteria, ask, "Can someone else do this for me?" If so, delegate it. If not, your final question should be, "What is the easiest way to accomplish this?" Sometimes we make things harder on ourselves than they have to be simply because we don't take time to figure out whether there is an easier way.

Once you have fine-tuned your list, look at the remaining items and try to accomplish at least a portion of your plan each week. Accept the fact that you will have some bad days. Allow yourself extra time in your schedule so that one or two bad days will not ruin your entire holiday season. By not waiting until the last minute to do everything, you might just have enough energy left over to actually enjoy the holidays.

Give yourself a G.I.F.T. this year and have a happier, healthier holiday season!

Six Tips to reduce holiday stress

- 1) Avoid the stress and exhaustion of holiday shopping by ordering your gifts from catalogs and TV shopping channels. An added benefit is that out-of-town gifts can be sent directly to the recipients, saving you the hassle of finding a box, packaging the gifts and waiting in line at the post office.
- 2) Use gift bags instead of traditional wrapping. (Dollar-type stores, catalogs and TV shopping channels often offer low-cost assortments of gift bags.)
- 3) Each year, between busy schedules and increased postage costs, fewer and fewer people send holiday cards. If you still feel you must send some cards, be selective. Only send them to close friends and family whom you seldom see.
- 4) When everyone is coming to your house for dinner, ask each one to bring one or two dishes, leaving yourself only one or two simple items to prepare.
- 5) If you are going out of town to visit relatives for the holidays, consider staying at a hotel for at least part of the time. Having a separate haven will reduce your stress by giving you a sense of control over your own space and activities for at least a portion of each day.
- 6) If the demands of your extended family are more than you can handle each year, consider making an annual holiday vacation a new family tradition. (Try a western dude ranch, a chalet in the mountains, or a warm tropical beach.) This can be a special bonding time for you and your immediate family. You will not feel compelled to cook, and you will probably reduce the size of your gift list because everything will have to fit in a car or on a plane.

Next Meeting

The next meeting will be held on December 19th. Agenda and Hot 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: Nancy Visocki at ngv.njcfsa@verizon.net, Judy Machacek at judymachacek@msn.com, Pat LaRosa at pcl.njcfsa@gmail.net 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 decided 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 other members.*