



Bergen ME/CFS-FM Support Group Newsletter

Meeting

Once again, the meeting featured a speaker from the Center for Integrative Healing at Englewood Hospital and Medical Center. Nutritionist, Nancy Cooper, RD, discussed healthy choices particularly related to ME/CFS and Fibromyalgia. One consideration is a variation of the Mediterranean diet – which includes fruits, vegetable, grains, berries, moderate animal protein, and a daily small handful of nuts.

Nancy Cooper also spoke for the benefits of tea and the choice of color is not an issue. Teas rank as a source of high amounts of antioxidants. These benefits are not present in “herbals teas” – which are not really teas. Decaf tea may not have the antioxidant properties.

The group engaged in a discussion of supplements, with many of those in attendance sharing their experiences with various supplements and suppliers. Nancy Cooper suggested that people should have Vitamin D levels checked – especially during the winter. Sunshine is the source of this vitamin and deficiencies are common at his time of the year. Milk products do contain vitamin D, but some people need additional supplementation.

Surviving the Holidays

The holidays can be an exciting and happy time, but people with ME/CFS/FM often need to take precautions in order to survive. For many it will be a time of push – crash, requiring varying amounts of recovery time.

- Pacing is key.
- It may help to make a list of things you wish to accomplish.
- Decide which things are most important and those that can be eliminated if necessary.
- Shopping online or by phone might be a good option.
- If you are hosting a holiday gathering, consider catering or having guests bring a covered dish. Disposable dishes could simplify cleanup.
- If possible, set-up the day before the gathering to allow rest time.
- After the party, put away the food and leave non-essential cleanup for the next day.
- Build rest-time into your schedule.
- Relax...do what you can...don't worry about what you cannot do...enjoy your holidays.

Sharing Holiday Joy – UPDATE!

There are many children for whom the holidays are not like the pictures portrayed in the media. Without angels, many of them might not receive any gifts. Each year, Attorney Barbara Comerford works very hard to make sure some children have wonderful memories to treasure by hosting parties and distributing gifts. Last year some of you helped her efforts by donating toys. **Barbara has amended her request. Her focus this year will be a program that serves toddlers through 4 year old children.** “Any toys would be greatly appreciated. Thank you!” Donations can be brought to the Bergen Support Group December luncheon. You can also contact us at pcl.njcfsa@gmail.com for other arrangements.

Request

We know that this newsletter has readers outside the state of New Jersey and we are pleased that you choose to do so. The NJCFSA, our parent organization, has had a request for help from someone in Arkansas. This person is looking for a physician who diagnoses and treats ME/CFS. The patient is a teen, so it could be a pediatric specialist or someone who treats adults. If you have names of physicians in that part of the country, please send an email to pcl.njcfsa@gmail.com or call the NJCFSA Helpline 1-888-835-3677.

Publicity

<http://consults.blogs.nytimes.com/2009/11/24/expert-answers-on-chronic-fatigue-syndrome>

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Expert Answers on Chronic Fatigue Syndrome

By [**THE NEW YORK TIMES**](#)

Denise Grady, a science writer for The New York Times, recently explored the link between a recently discovered virus called XMRV and chronic fatigue syndrome, in [“Is a Virus the Cause of Fatigue Syndrome?”](#) Here, Dr. Nancy G. Klimas, who serves on the board of the International Association for Chronic Fatigue Syndrome, responds to readers’ questions. Dr. Klimas is a director of the department of immunology of the University of Miami School of Medicine and director of research for clinical AIDS/H.I.V. research at the Miami Veterans Affairs Medical Center. See her earlier responses in [“Readers Ask: A Virus Linked to Chronic Fatigue Syndrome”](#) and Fred Friedberg’s responses to behavior-related questions in [“Behavioral Treatments for Chronic Fatigue Syndrome.”](#)

When Chronic Fatigue Syndrome Goes Undiagnosed

Q. Dr. Klimas, do you have any thoughts as to how many C.F.S. patients are under the radar because they were not eager to sign up for a “wastebasket” diagnosis, or otherwise frustrated out of the medical system early on?

There are many other labels that would be easier to deal with: chronic Lyme, depression, etc. What are the ramifications of an actual clinical diagnostic test for C.F.S. on the medical and patient communities? Can you foresee any possible unintended consequences?

Skeptic

A. **Dr. Klimas responds:** Currently only 16 percent to 17 percent of the people with chronic fatigue syndrome whose symptoms are severe enough to meet the case definition for the illness have been diagnosed. Whether this is coming from the patient, as you suggest, or a medical community that does not know how or is reluctant to make the diagnosis is less clear.

Leonard Jason’s group in Chicago has done studies with health care providers and shown that the clinicians most likely to be familiar with the disease are those with a family member who is ill. He also

did a study showing that the name “chronic fatigue syndrome” influences a physician’s sense of illness severity. When the same constellation of symptoms were give other names, providers in a study responded that the illness was a more serious health problem than C.F.S.

To hear more from Dr. Jason, see this interview, [“Learning Firsthand About Chronic Fatigue Syndrome.”](#) in the Times Health Guide.

Can Vaccines Set Off Chronic Fatigue Syndrome?

Q. I often felt that I was on my last day with C.F.S. but have been fortunate enough to have long remissions. I was diagnosed with C.F.S. in Los Angeles in the ’80s. However, in 1995, I was given the newest polio vaccine to go to Turkey, and within six weeks was deathly ill. I had lost my cognitive skills slowly, forgetting what city I was living in, where my job was, what floor it was on, what account I was working on. I couldn’t read as the words and font changed. Driving meant possible crashes. Walking was like severe vertigo. Pain felt like punches and deep wounds and the fatigue was mono on steroids.

I go into this wondering whether the polio vaccine exacerbated the virus. I see postings about C.F.S. and the polio vaccine on Google, but was wondering whether anybody else has had these experiences. I have recently gone into a new relapse after a long remission (gratefully), and now I’m angry. Hurry please — the one and only doctor in Toronto who deals with this illness is taking no new patients. I’m alone and looking like a bit of a hypochondriac.

LJC

Dr. Klimas responds: Over the years I have seen a number of individuals who have developed chronic fatigue syndrome after receiving a vaccine, most frequently the hepatitis vaccine, yet the vaccine safety studies have not noted enough cases for the link to be statistically significant. Some researchers have also examined a possible link between vaccines and Gulf War Illness, a C.F.S.-like ailment observed in those returning from the Gulf war in the early ’90s. That link has been difficult to prove one way or another, as the military no longer vaccinates troops with such a large number of vaccines at one time.

So while I can theorize, as an immunologist, that a person predisposed to chronic fatigue syndrome who is exposed to a big enough immunologic kick could start an immune-mediated process, like autoimmunity, or reactivate a virus or viruses, we haven’t the proof. Still, when I hear your story, it makes me think that we simply don’t know enough yet.

Chronic Fatigue Syndrome Outbreaks?

Q. Have there been clusters or outbreaks of chronic fatigue syndrome, as some have described? And if there were outbreaks, doesn’t that make it more likely to be contagious and less likely that the exposure came “from exposures between great-great-grandparents and maintained for generations as latent infections, or as infections from early experiences of any sexual partner in a chain of partners?”

If there were outbreaks, it would seem odd that latent infections from past generations reactivated in a cluster at the same time. I guess another possibility might be that a second contagious virus or microbe comes along and reactivates the latent virus.

Claire

Dr. Klimas responds: These clusters of post-infectious chronic fatigue syndrome are very interesting. Studies by [Andrew Lloyd and colleagues](#) showed the one and only predictor of persistent illness after an acute infection was the severity of that initial infection. No psychiatric factors were shown to predict who remains ill.

Some very common infections seem to set off C.F.S. and lead to several theories about the disease. My favorite theory is that any infection that can activate the immune system in a profound way could allow a hidden latent virus or viruses to reactivate and perpetuate a chronic illness. Anything that suppresses the immune system, like some treatments for cancer, might do the same thing, causing profound fatigue in some “recovered” cancer patients years after chemotherapy.

But why can one person do well and another stay ill after the same infection? Genetics may play a role, but this concept of a vulnerable population with latent XMRV infection is intriguing.

Are There Two Viruses Linked With Chronic Fatigue Syndrome?

Q. Dr. Klimas. I really want to know more about what you think of the specific findings of Dr. DeFreitas. Do you think there are two retroviruses associated with CFIDS? I know there needs to be more study, but do you have an educated guess as to how they interact and if they are causative or just epiphenomena?

For example, if this were solely hypocondriasis or conversion disorder, I would want to know so I could start therapy on it. Justin Reilly

A. **Dr. Klimas responds:** [Elaine DeFreitas's work](#) and that of [Dr. Michael Holmes of New Zealand](#) both involved scanning electron micrographs of viruses. Their findings look a great deal like those that were published in the recent Science article by Dr. Lombardi and colleagues, which [Ms. Grady wrote about in The Times,](#)) that found a possible link between chronic fatigue syndrome and the XMRV retrovirus. Could they be looking at the same virus? I don't really know, because I am not a laboratory virologist. But it makes good sense to me.

I remember in the early 1990s a member of our laboratory, Dr. Roberto Patarca, found evidence of production of an enzyme called reverse transcriptase in our cell cultures, more evidence of an active retroviral infection. So the key thing now is for another reputable lab to find the same thing in chronic fatigue syndrome. Then we will see what happens next.

Accuracy of Current Results

Q. Dr. Klimas, I find the new research hard to believe, especially the follow-up research that shows 98 percent of patients who receive a clinical diagnosis of C.F.S. tested positive for the retrovirus, compared with only 3 percent of controls. Why hard to believe? It is almost impossible to be 98 percent accurate with most clinical diagnoses, especially those without specific tests, like C.F.S. Please comment.

Jack

A. **Dr. Klimas responds:** Well, it is hard to comment on unpublished data — the number of patients who were shown to be positive for C.F.S. by antibody testing has not been established. There are likely to be wide differences when these prevalence studies come out — as you point out, where the investigator gets the blood will matter. Investigators will need to be very clear how they defined the illness, where they got the samples, the demographics of the population, and any defining subgroup information.

In my clinical immunology clinic, for instance, there may be more patients with a post-viral or acute onset type of C.F.S. than other medical practices. A rheumatology clinic, for example, may have a stronger fibromyalgia overlay to the population.

In the [population-based Georgia study conducted by the Centers for Disease Control and Prevention](#), investigators used a broader case definition and identified a population with C.F.S. that was fivefold larger than previous prevalence studies. That study may have included people with other disorders that cause fatigue, and I would expect to see up to a fivefold difference when compared with a more tightly defined group.

There may also be regional differences in the prevalence of the XMRV virus that was recently linked to C.F.S. [A European study](#) that failed to find the virus in prostate cancer samples suggested that there might be differences in the background population prevalence rate of the virus.

Next Meeting

The next meeting will be held on Sunday December 20th. As has been the custom, it will be a holiday party and you are invited to bring something for the sharing table. In the past, members have brought a wide variety of goodies to the table, from appetizers to desserts. You are welcome with or without donating toward the sharing table. It is a nice time to get to chat with other members.

To all our members: – in person and online - we wish you a Merry Christmas, Happy Chanukah, Happy Kwanza...Happy Holidays!

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.njcfsa@gmail.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.

WEATHER – 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 lunch gathering. This is an informal gathering, an opportunity for people to gather and chat with other members.