

Lyndonville News

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Information and Support for the ME/CFS/FM Community
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Introduction

Greetings from Kumamoto, Japan where I happen to be killing time in an internet café during the evenings after the presentations from the 4th Japanese Fatigue Society Meetings. But rather than turn this into some sort of blog (I am not really sure what exactly a blog is), I would like to send out some material that has been accumulating over the past six months. I apologize for the lack of issues of the *Lyndonville News*, but that's the way it goes. I am taking copious notes from the meetings and hope to send them out in a newsletter in the near future, but I have promised that sort of thing before so don't hold your breath.

Cellular Hypoxia Book

I have gotten lots of feedback from readers about the new book, *Cellular Hypoxia and Neuro-Immune Fatigue*. I appreciate the comments and hope that the concepts presented will grow into an effective treatment strategy. Anyone interested in the book can send \$25 to David S. Bell MD, 1276 Waterport Road, Waterport, NY 14571. There have been some requests from overseas, and if they wish, they can get a US bank draft or money order for the same amount. It turns out that the mail gets delivered to Europe faster than to places within the US. Go figure.

Office Matters

I am continuing with the changes in the office and struggling with cutting back on my regular practice. I may "sell" my regular practice for \$1.00 to a nearby clinic. After thirty years of practice that's about all I can get for it. One of my regular patients heard about it and indignantly said that he was not for sale. I doubt I could have gotten a dollar for his body parts anyway.

Over the years my patients have been very kind to me, at least most of them. Here is a poem from a ten-year-old-boy.

To Doctor Bell:

I'm going for a check-up,
I'm healthy (Mom says I'm not)
They weigh me and take my temperature,
I hope I don't need a shot!

I did need a shot,
But I have a whim.
That I can give the doctor a shot
When I'm as old as him.

-Oliver

Name Change Issues

As many of you are aware there is ongoing discussion of the name of this illness, and the *Campaign for a Fair Name* has a web site at www.afairname.org. A petition is presented there and a vote will take place in March. I would encourage as many of you as possible to be involved. Personally, I would like the name issue to be settled one way or another so we can get on with it.

Clinical Notes

Questions continue to come in about the Stanford study and the use of Valcyte. We have no further information from the study as yet, but a patient of Dr. Lucinda Bateman is writing a blog that is available on the OFFER website that might be of interest. It seems that we are all holding our breath in hopes that this is going to work.

Conference Reports

I had the great good fortune of seeing a personal milestone passed with the recent conference in Oslo, Norway. I can remember twenty-five years ago hearing someone say that in the future there would someday be medical conferences packed with health care providers studying how to diagnose and treat ME/CFS. I can remember being a little dubious. But now I can say that I have seen it come to pass.

The Oslo conference was two days; the first day for patients and support persons, and the second day was for health care providers. On that second day the conference center was packed with over 450 health care providers. We heard presentations on an outbreak of ME/CFS in Bergen, Norway, and numerous other review talks. It was extraordinary to see so many health care providers eager to learn about ME/CFS. A representative from their health department cancelled a number of appointments so that she could stay and hear the entire proceedings. I have a hard

time remembering when that ever happened in the US. Congratulations to Ellen Piro and the Norwegian ME Association.

Case Reports:

John is 85 years old, and showed up in the office for a follow-up check after twenty-five years. I saw him for a few visits in 1982, and he had been ill then for about twenty years. It had started with mononucleosis somewhere in the 60's, and he never quite recovered. His course is a textbook of the natural history of the illness, good news and bad news. The timid and those persons assuming that ME/CFS/FM is a benign illness might elect not to read this section further, as John's illness did not disappear. Some years ago the CDC published a paper saying that ME/CFS is not a progressive illness. They have not followed it long enough.

Like most persons with an acute infectious onset, John was very ill for a couple of weeks and then seemed to get better. He got up to around the 70% activity mark and was doing pretty well, and then crashed. For the next two years he was quite ill but slowly, very slowly began to improve. He endured hundreds of tests and even more comments about how he was probably "under some stress" or depressed. It was, after all, the 60's, and physicians had not yet become familiar with ME/CFS. But even in his 40's, John was a tough old bird, and he got along with his life as best as possible.

When I first saw him his activity was clearly reduced to about 40% of normal. He had all the classic symptoms, but his spirits were good, and he had some support from family and friends. Eventually he got social security disability, and, while he was not pulling in the big bucks, he got by.

There were ups and downs. The good times were characterized by a few days at a time of pretty good activity where he could get out, visit friends, read and study. As the years went by the degree and length of the good times slowly decreased. The degree and length of the bad times slowly increased. John was always dedicated to physical exercise, and he employed common sense. One of the most difficult days of his life was the day he could not get back to his house after a short walk. As the years progressed he used a wheelchair more and more. Yet when I tested his muscle strength on the examining table it was normal. The problem in ME/CFS is the inability to sustain activity.

John's illness and its slowly progressive nature were not a surprise to me. But what caused me to sit back and listen in admiration was the strength of the human spirit. Despite the difficulties, the lack of recognition, and the physical symptoms, John not only maintained his dignity, he was able to find meaning and many moments of joy over the past 50 years. John is my teacher. New cars, money, social stature and daily comforts are insignificant when stacked up against the success of the human spirit. If and when I reach the tender age of 80, I hope I will be able to say I have accomplished as much as John.

History

It has only been recently that I have become aware of Sophia's story. It is a nightmare that has been written by Sophia's mother concerning her daughter's illness and death. The story is available on the Invest in ME website (investinme.org). Like many families struggling against this illness, Sophia's mother was told by her physician that "I was keeping her ill and as long as I was looking after her she would never recover." Sophia was forcibly removed from her home and put in a locked psychiatric ward. After prolonged difficulties Sophia passed away November 22, 2005. The initial autopsy showed no cause of death, but further tests showed "unequivocal inflammatory changes affecting the special nerve cell collections (dorsal root ganglia) that are the gateways (or station) for all sensations going to the brain through the spinal cord. The changes of dorsal root ganglionitis seen in 75% of Sophia's spinal cord were very similar to that seen during active infection by herpes viruses (such as shingles)."

It is hoped that Drs. Chaudhuri and O'Donovan will identify the cause of the spinal cord damage and publish their results. But will the medical community listen? Could it be that the ganglionitis was caused by a herpes group virus like ones being studied in the Stanford study? I pray that no one with severe ME is ever forcibly incarcerated in a mental hospital again, and I pray that Sophia may rest in peace.

Lyndonville Research Group Report

We had a meeting of the Research group to pull data from treatment results using standard medical (symptom reduction) treatments. While the numbers have yet to be properly crunched, it has been my feeling that the standard medical approaches have not resulted in a significant improvement of activity. Certain symptoms are clearly better, and among them are the sleep quality and pain. But the key issue for quality of life for persons with ME/CFS/FM is the level of overall, productive activity. The first study that we are going to do is to compare the level of symptoms with standard medical treatment and the level of symptoms with high dose B12 treatments. There is no doubt that some people respond to this treatment. The question is how to predict who will respond and how to improve the responses of those who do not respond. Two members of the Lyndonville research group are combing the medical libraries looking for information on high dose B12. They are moles, burrowing into the literature. If we should come up with anything, we'll put it in a future issue.

Question and Answer

Question: *I was fascinated by the clinical notes in the last issue of the Lyndonville News. The comment regarding the 2 types of CFS is the sort of observation that could seem obvious to clinicians, while still being overlooked in empirical research, and even obscuring many studies' results. As a side-note, I've read a lot of scientific CFS literature since being diagnosed myself, and I haven't come across anything as thought-provoking as your Faces of CFS. I wonder if many CFS researchers are skeptical about case-studies because they may seem non-scientific; however, such detail, I think, is very productive.*

What particularly interested me about the notion of a frazzled subtype is the potential role of epinephrine in CFS. Some recent studies have found propranolol useful in treating CFS and FM. This treatment struck me as a little counter-intuitive; that is, what doctor would be cruel enough to deny adrenaline to patients who can't get out of bed? If propranolol ends up being very useful, you can see why it might have been overlooked.

But I think there are a couple of general and specific connections between epinephrine and CFS symptoms, which play out in the literature on propranolol. Propranolol's effect on POTS is well-documented, but the drug probably also boosts immune functioning, reduces inflammation in certain circumstances, regulates sense and pain perception, eases digestion (particularly of carbs), and increases the threshold for exertion. Epinephrine's negative effect in these areas could fuel a self-reinforcing cycle, like Pall's NO/ONOO cycle. Moreover, anecdotal risk factors for CFS, like long-term exercise and type A personality, probably involve increased epinephrine.

Lastly, it's also curious to think about propranolol in terms of all the obtuse research that favors psychological treatment. This is because epinephrine can be consciously controlled to a small degree by, for instance, self-awareness and breathing slowly. However, if the long-term benefits of psychological treatments ultimately lie in teaching patients to control epinephrine release, then propranolol would be much more effective.

Answer: A very interesting set of questions. First of all, adrenalin (epinephrine and/or norepinephrine) is very involved in the illness, particularly the frazzled subtype. It can be measured after simple standing, and when it is over 600 it is considered abnormal (Hyper-adrenergic). It is my observation that treating patients with this type with any medication (coffee, stimulants, midodrine) which increases adrenalin, they get worse.

Secondly, I don't think beta blockers such as propranolol do very much good. The hyperadrenergic response is a response – it is trying to improve a sad state of affairs, and when it is blocked, patients don't seem to feel much better. Their chest pain goes away, though. CT scans of the adrenals show that they are small, thus the name “adrenal fatigue”, probably because they have been squeezed for so long.

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