

Lyndonville News

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

Time flies. And it seems to be speeding up with increasing age. It has been over a year since the last *Lyndonville News*, and on several occasions I had tried to abandon it completely. Like most people, I blame all this on the stress.

It has been four years since I decided to "retire". It has been 35 years now, time for a change. I dearly love my patients in Lyndonville and I hope they will knock on the door of my house when they have questions. But I can no longer run an office and fight with insurance companies whenever I want someone to get an x-ray. So I put the practice up for sale for \$1. And now, four years later, for the first time in over thirty years I am free!

But it was a struggle. Physicians are leaving upstate New York like lemmings going somewhere urgently, and no one wanted a solo practice way out in the countryside. But finally, a wonderful and altruistic organization called Oak Orchard Community Health Center out of Brockport took it over. It took a few years and we were able to settle on fifty cents rather than the one dollar asking price, but it was worth it. I am free at last! Well, I am now an employee for Oak Orchard. Two to three half days a week, as long as I promise not to diagnose anyone with CFS. Also, the time is carefully computerized so I cannot talk with anyone for more than 12.23 minutes.

There is one problem with the clinic, however. Everything, all the records and labs are computerized, and it is very difficult. Have you ever tried to carry on a conversation with a teenager playing a computer game? Well, it's going to be like that when you talk to your doctor from now on.

Actually I have a plan. Now that I have lots of free time I am going to be bored. So I plan to do a few things: a) legal work for patients who have been badly injured by the system just because they got sick, b) write some more books, c) put out a few issues of the *Lyndonville News* again, and d) really start studying CFS for the first time. I may see a few patients with CFS now and then and really go to town. I haven't worked out the details yet. But I promised a few kids that I would never abandon them, and I mean to keep this promise. We'll see what happens.

Literature Review

While it is not really breaking news, I wanted to put out this edition of the *Lyndonville News* to talk a little about the Myhill/Booth/Mclaren-Howard study. This study published a few months ago examines the bottom line in energy production, ATP production and utilization. In my opinion it is likely to be a landmark in the future. As noted before, there have been many studies looking for and finding oxidative stress in patients with CFS. However, this study looks at the end product of energy metabolism in five ways, using three separate measurements. The results of these studies show variations in individual metabolic profiles, but only one out of 71 patients were similar to healthy controls. Thus there is heterogeneity in CFS, but the overall result is reduced energy production. In other words there are likely to be different ways that energy production is compromised in CFS patients.

Their tests relied on the long history of testing for oxidative phosphorylation, and as such should be reproducible. They tested for availability of ATP in neutrophils, ATP fraction complexed with magnesium (the fraction which is available for energy), the efficiency of oxidative phosphorylation, the ability to transfer ADP into the mitochondria for utilization, and the ability to transfer the ATP into the cytosol where it is utilized. Abnormalities were seen in each area, but there were differences between patients in which area was abnormal. To neutralize this heterogeneity, each test was given a numeric factor, and the results were added together for a numeric "ATP profile". It was in this overall profile that patients differed from controls.

Another important variable used in the analysis was to compare the mitochondrial function with an overall activity profile, the Bell Ability Score (see appendix). The purpose of this was to see if there was a relationship between reduced ATP production/utilization to illness severity. There was a clear with a $P < 0.001$. This paper offers one method of subgrouping patients with CFS based upon the variables tested.

As with all other encouraging notes on the research on CFS, I caution patients not to get their hopes up. While this is another "diagnostic test", it does not immediately open up doors to successful treatment. But it does point the way to distinguishing specific "types" of CFS, if only this were pursued. Myhill S, Booth N, McLaren-Howard J. Chronic fatigue syndrome and mitochondrial dysfunction. *Int J Clin Exp Med* 2009;2:1-16

Old-Timer's Section

I have always enjoyed the old timers in my practice. I will miss them badly as I retire. An old timer is a patient with CFS who has seen it all come and go. They take the successes and failures in stride. They have given up trying to convince their skeptical relatives they are ill. They do not even mind the insults from the short-sighted, inadequate, and misinformed physicians they see for their bone density tests and cholesterol screening. They cope so well that it no longer requires special planning. A few are bitter.

But a few have come into acceptance. They would not mind a cure or even a good treatment or two, but they are no longer depending upon it. What is amazing to them is that they felt that they were dying for the last thirty years, but they haven't died. What's more, they may not die anytime soon. This is the old joke about CFS - "There is good news and bad news: the good news is that you are not going to die anytime soon, and the bad news is that you are not going to die anytime soon."

The old timers have put it into perspective. The government is not going to do much about CFS, their doctors are not going to read articles about it. But there are worse things in the

world. No one much cares about the genocide in African countries; few care about the wars we are fighting to get the weapons of mass destruction that don't exist; few care about the homeless in the richest country in the world. The old timers watch and the time passes. Some of them don't even feel sorry for themselves because of the lot that fate has been cast for them. Some of the old timers are lucky.

Patient's Observations

I was fascinated by the clinical notes in the last issue *Lyndonville News* clinical. 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.

Another Note From a Patient Having the 2 Day Exercise Test

The first day of the exercise test: I had some symptoms of a migraine the first afternoon but was able to ward it off with coffee and Tylenol™. I was more tired than usual, and quite sore. I got a massage, stretched and relaxed.

The second day of exercise. Immediately on completion of the test I was affected cognitively and so tired I did not feel I could safely pick up and hold my 2-year-old son. I napped as my husband drove us home, and that afternoon I had a full-fledged migraine and was

bedridden. I was very fuzzy minded, and I had trouble speaking. I was not capable of driving 10 minutes the next day to drop my son at daycare, so my husband had to take another day off work.

The day after the second exercise test I had a saline drip. I was still in a total fog, and felt so exhausted that I thought I would topple over at any minute. Although the migraine had resolved, I could barely find the words to speak simple sentences, and I had trouble raising my eyes to make eye contact. Upon receiving the first saline drip, I could feel a significant difference about halfway through the 1 liter bag. My mind was returning! I was still extremely tired and my pain level had not changed much. But the saline helped with almost immediate improvement in cognitive functioning.

I did receive a second bag of saline the next day but I did not notice further recovery. Altogether it took two weeks to return to my previous state, my "normal." I hope this helps others who wish to brave the test.

Contact: If you wish to contact Dr. Bell, e-mail to lynnews@davidsbell.com; very few inquiries are answered, but comments are welcomed.

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