

Lyndonville News

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Information and Support for the ME/CFS/FM Community
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Cellular Hypoxia in Neuro-Immune Fatigue

Introduction

Well, the book is finished. And it carries the awkward title of *Cellular Hypoxia in Neuro-Immune Fatigue*. Don't panic. While this is a somewhat intimidating title, I hope that by reading it, persons interested in FM/CFS/ME will get a picture of where the science is leading in the past few years. It may seem like a jump, but we are all a little beyond the standard description of symptoms.

It is not a book for rookies and has little introductory material, meaning that it should not be given to aunt Tille who needs to learn about CFS. It is a small book, only 120 pages, but I hope that by leaving out tons of scientific detail, the concepts about what takes place inside the cell may become clear. It describes a theory that fibromyalgia and ME/CFS are parts of a spectrum of illnesses, called here Neuro-Immune Fatigue, and that the common end pathway of these illnesses is a dysregulation of cellular metabolism leading to the inability of the cell's mitochondria to utilize oxygen.

Lost already? I have tried in this book to make these concepts as reader friendly as possible. And the material is not new. Drs Martin Pall and Paul Cheney and others have been talking about this for years. I do think that the whole confusing conglomeration of ME, CFS, chemical sensitivities, fibromyalgia, orthostatic intolerance, chronic Lyme disease is ready to be understood with the science we have today. If no one should ever buy this book, I will be content. I really wrote it to sort out my own thinking on the subject. And in the process I hope this will be useful to others. My life's dream will be fulfilled if it helps scientists and clinicians make the next step in what I perceive to be the direction the research is heading. For those of you who are interested, in past issues of the *Lyndonville News* a few first drafts of chapters were presented. (Available free at <http://www.davidsbell.com/DSBNewsletters.htm>)

So, if you really want to buy this book, send me a check for \$25 to 1276 Waterport Road, Waterport, NY 14571, and I will mail you a copy within a day or so. The science is now coming in

fast and furious, and at the very least this short book will serve as an introduction to the complex new science of cellular energetics. For those of you who purchase the book, I would be eager to hear your comments and suggestions at lynnews@davidsbell.com.

On The Farm

A number of you wrote with surprise or dismay about my coming retirement, where I would be able to gaze out the back porch to the fields of hay being baled now as we talk. I appreciate the warm thoughts that are expressed, but I do not think it is time for alarm. I plan to close my regular practice, but hopefully continue to see patients with ME/CFS, and even explore new treatments. But it is time to write. I don't know whether it will be good writing, nor do I know if it will be effective. It is also time to dive into the mechanisms of cellular energy production. I am interested in any thoughts as to how to distribute the information. Here are a few ideas of projects.

I am beginning work on a very short book entitled *Chronic Fatigue Syndrome and Fibromyalgia: A Short Treatment Guide for the Primary Care Provider*. This book is short (around 50 pages) and reader friendly, designed to be given to a primary care provider respectfully by a patient with ME/CFS or fibromyalgia in order to communicate in a simple and direct way some of the treatment approaches that experienced clinicians have put in place for some years now. The approaches will not be just my own, I hope to discuss and interview many of the foremost clinicians for their ideas on such subjects. I hope to have it written in six months or so. Another book that I hope to write is a re-write of the *Doctor's Guide to Chronic Fatigue Syndrome*. I can't believe that that book is twenty years old.

Clinical Notes

The clinical notes for this newsletter is kindly suggested by a reader who sent information to the website. It is extraordinary how much knowledge and information is available, and really needs to be collected and presented. It is because of this that I would like to re-organize the research group (see below).

For years I have said that clonazepam is perhaps the most useful medication in ME/CFS, and because of the notes of a reader, I now understand why. Clonazepam is a medication distantly in the anti-seizure and benzodiazepine class. I say distantly because it is different from Xanax™ or Valium™. Clonazepam has a long duration of action, and is more gentle. It has no euphoria and I have never seen anyone become addicted to it. In some patients and in the right dose it improves the symptoms of ME/CFS, particularly sleep and general malaise; for some, it increases energy and activity.

The effect in reducing fatigue has always been confusing, as it is a medication that should cause tiredness. Persons with ME/CFS should not be able to tolerate it. There are two broad categories of ME/CFS; one is the "heavy as a log" tiredness where it is easy to fall asleep, and persons drink

coffee to stay awake. This type of CFS is milder, and relatively easy to treat. Clonazepam does not help in this type. The second type is the “wired and frazzled” where despite exhaustion, persons cannot sleep and they are unable to take any stimulants. Clonazepam can help in this type and it is not because of the simple explanation of anxiety. This type of ME/CFS is neuro-excitatory, and it may be that the benefit is related to effects of clonazepam on the sympathetic nervous system. My thanks to the kind reader who sent in the information and references.

Guest Editorial

A flick of a light switch changed my life. Too dramatic? Maybe.....but not from my perspective. I was officially diagnosed with Chronic Fatigue Syndrome in 1990 and have struggled with all the usual symptoms and all the typical problems that go along with trying to cope with any chronic illness. I've worked part-time since 1993 and have had many different supervisors: some supportive, some oblivious about my health, one downright mean. I experienced a fairly steady course with my symptoms and learned how to balance my life pretty well. I was able to do most things I wanted to if I moderated everything carefully.

Just about a year ago, the symptom that began torturing me on a daily basis was dizziness. It was an indescribable sensation that threatened to upset the carefully crafted balance of work vs. rest that enabled me to function in all the roles that are so important to me. After months of frustrating visits to various specialty doctors, I was able to get confirmation of what Dr. Bell had initially suspected: I was having daily migraine symptoms.

Early on, I had noticed fluorescent lights made the dizziness worse. I became excruciatingly aware of how frequently we encounter fluorescent lights in our daily lives. My husband had to take over the household shopping, (one more thing he had to take on) since stores are lighted with fluorescent lights.

I work in a school, where there is an abundance of fluorescent lights. I was determined to keep working. I took floor lamps into my office and kept the overhead lights off....what a relief. But much of my work is done in other areas of the school building. One day I casually mentioned to my principal that the fluorescent lights bother me. She immediately stood up, walked over, and turned off her office lights. She has an inside office with no windows letting in natural daylight, so we sat there talking in the dark. It brought instant relief for me! (If you've never experienced the dizziness, nausea, and headache caused by migraine triggered by fluorescent lights, count your blessings!). Not only did I have the relief of not being under the fluorescent lights, but I also knew I didn't have to pretend to be feeling okay. I felt valued as an employee and respected as someone who has something to contribute even if I have a special need (for the lights off). Not only does my principal turn her office lights off, but she makes it a routine to adjust the lights in other rooms if I am present. It may not always be practical to have all lights off, but she makes sure they are adjusted as much as possible.

I have tried to articulate to my principal just how much her casually flicking that light switch has meant to me. She waves away my comments, saying, "it's nothing" or "don't mention it". What it

means to me is this: a chance to keep working at a job that means a lot to me; I'm able to provide financial support to my family; I'm able to continue the important social contacts in my workplace; I'm able to have the intellectual stimulation of working; I'm able to feel like a productive member of society.

This isn't meant to be a criticism of anyone who has chosen to seek Disability benefits. Those benefits serve an important function for many people. I just wasn't ready to seek those benefits yet. Thanks to my principal making a simple accommodation - just a flick of a light switch - I can continue working, with all the many benefits that provides me. Jean Gargala

Lyndonville Research Group Report

The Lyndonville Research Group is beginning to get going again. For those of you who are part of the group, this is your official notice. In the book that is now coming out, *Cellular Hypoxia and Neuro-Immune Fatigue*, a mechanism is described relating to the cellular production of energy. Now, people casually assume that a few vitamins will correct this and I do not think that is likely. What we are going to try and do is a thorough reading of the literature on cellular energetics and mitochondrial energy production to see if we can find areas where specific interventions may be useful. Ultimately we are trying to identify specific types of ME/CFS that might respond to certain treatments.

Here is an example: full thiamine deficiency is rare because of generally good nutrition, but some persons have a defect in the enzyme system that uses thiamine and as a result have dysautonomic symptoms. This can be detected with an erythrocyte transketolase index, where a thiamine pyrophosphate (TPP) stimulation test greater than 14% demonstrates thiamine deficiency. This illness, caused by an enzyme abnormality can be effectively treated by giving very high doses of thiamine which bypass the defect.

Here is the good news and the bad news. The good news is that many types of ME/CFS might be treated by finding one or more specific defects in the energy production system and treating it appropriately. The bad news is that there may be hundreds of these potential spots, all of which can end up with a reduction of cellular energy. The research group's job is to research, catalog, and put together these potential mechanisms, figure out how to test people for them effectively with existing medical insurance, and, if a specific defect is found, treat with existing methods.

Here is how I would see it working. One, two, or three persons would tackle the thiamine problem described above. They would access the data on line, print out references, find out where the erythrocyte transketolase test could be done and for how much, fax the material to the central collecting person. We would have meetings every once in a while, but the meetings are not essential so even persons with moderately severe illness could participate. Skills required would include sincerity, desire, internet skills, and ability to see the portion tackled through to the end.

This is a project with an extremely low possibility of success; it is hard work, unpaid, and will be unappreciated. Most of the work will be via internet and medical libraries. Data will be collected in

our office, organized and posted on the web site to be used for free by anyone interested. It might work. We'll think about it. Anyone interested can contact me.

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