

Lyndonville News

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Information and Support for the ME/CFS/FM Community

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FLORIDA CONFERENCE

Introduction

Well, it is another new year. Happy new year everyone, and I hope that your holidays were enjoyable. This issue of the Lyndonville News is a bit of a summary of the conference of the International Association for Chronic Fatigue Syndrome (IACFS) held January 7 thru 12, hosted by P.A.N.D.O.R.A. More detailed and balanced summaries will be in the IACFS newsletter.

The conference was wonderful. I got lots of pictures, and I will try to share as many of them as possible over the next couple of years. I want to identify some of the great minds that are trying to make progress in understanding this miserable illness.

Conference Reports – overview

The conference was perhaps the best ever. As before, there were two parts, a patient-oriented part and a scientific part. Both were superb. For those patients who were there, they will probably have a difficult next month trying to recover and process what they experienced, but it should turn out to be worth it in the long run.

The science is getting better and better. One presentation was the Miami erythropoietin trial. Good news and bad. First, 70% of ME/CFS patients have a low red blood cell volume. This was an NIH funded trial and solidifies the finding for use in the laboratory evaluation. The bad news is that treatment, while it brought the RBC volume up to normal, it did not help the symptoms very much. Some help to the orthostatic symptoms, but not fatigue. The meaning of this for me is what we have been leaning toward. The

low blood volume contributes to orthostasis and treatment of that is helpful, but is not the prime target.

Some persons clearly have persistence of virus in their brain, particularly Epstein-Barr virus and human herpes virus-6, and treating those viruses with the right drug may be very (very, very) helpful. There is a new project starting in California that intends to find out just how many persons with ME/CFS have this virus. But here's the problem (there is always a problem). Our local lab, and most others are hopeless when it comes to measuring for these viruses accurately. They are so bad it is not even worth doing. The good labs require cash for the testing, and it is unlikely that your insurance will cover the test at all. You would be able to deduct the cost of the test from your taxes at the end of the year, but the money has to go with the sample. This makes finding out who should be treated with the antivirals virtually impossible. Go figure, you spend \$7,000 a year for medical insurance but can't get the tests that are likely to be of help.

Lots of discussion of cellular hypoxia. This is the issue of oxygen being delivered to the cells of the heart, brain, skeletal muscles and other organs, but the process of turning the oxygen into energy is derailed. Mitochondrial, metabolic, cellular, glutathione, nitric oxide... we don't even know what to call this area yet. A complicated subject, and one that I would like to explore in greater detail in the office, but again, the testing requires cash up front for the laboratory tests. This is still quite new, and treatment aspects may not be ready for prime time. Dr. Paul Cheney gave a superb lecture on "Functional Hypoxia" as the keynote speaker of the patient banquet, but it may have been a little over the heads of the worn out, CFS-drained patient brains trying to eat dinner. It is my hope to attempt to translate this talk at some time in the near future.

Lots of very good talks on measuring different neuro metabolites and metabolic breakdown products in both ME/CFS and fibromyalgia. Tests of genes in the spinal fluid, lactate in the brain, holes in the heart, spectroscopic blips on serum samples. Good science which adds to our understanding, but not ready to become a simple test. Hang in there for another two to thirty years.

New pediatric diagnostic criteria. Very exciting. We now have an instrument that will be able to diagnose ME/CFS in children and adolescents. The instrument will be posted on the IACFS web site, and we will have it freely available in our office. Right now we are collecting data from all over the world. Next step is to publish in a good pediatric journal and make these criteria official. This is a very good science-based advance in the ability to correctly diagnose children and adolescents with ME/CFS (see Advocacy section).

The doctor-to-doctor session had a lively discussion of saline infusions, replacement of androgen and estrogen, sleep medications, environmental testing and other management issues. Very interesting, and practical.

History

In this conference, Staci Stevens, Dr. Mark Van Ness, Dr. Christopher Snell, Peg Ciccolella, and their group presented their test-retest exercise paper summarizing the results in six patients. I am including this summary in the history section of the newsletter because I believe that it is history in the making. It is the first time a clear proof of physical impairment has ever been presented to circumvent the controversy. For this reason I would like to describe it in a little more detail.

Peak oxygen consumption, percentage of predicted heart rate, and oxygen consumption at anaerobic threshold were measured on two consecutive days in 6 CFS patients and 6 sedentary control subjects and compared to accepted normal data. As expected, data for CFS patients and control subjects were not significantly different for the first day exercise test, consistent with previously published studies. However, on the day 2 exercise test, CFS patients had significantly lower VO₂ peak, and at anaerobic threshold. VO₂ peak: controls 28.9 +/- 8.0 ml/kg/min vs CFS: 20.5 +/- 1.8 ml/kg/min; Anaerobic threshold: controls: 18.0 +/- 5.2 ml/kg/min and CFS patients: 11.0 +/- 3.4 ml/kg/min.

Normal persons should have less than 8% variability in test-retest within 24 hours, and the sedentary controls demonstrated this low variability. However the drop on peak VO₂ and anaerobic threshold was substantial, in the range of 38%. These changes in day 2 exercise testing suggest a significant and verifiable physical abnormality in CFS patients, essentially verifying the symptom of post-exertional malaise.

The issue, of course, has been the need for patients to “prove” their disability to social security and private disability companies in order to receive benefits. In the old days, health care providers could write a letter saying that their patient was disabled but this no longer matters. Many health care providers have not spent years of research in CFS, and, while they know their patients, do not know how to prove the disability. Medical insurance companies will not pay for unusual laboratory testing such as the 2’5’A, and RNase L assays. Disability Companies disregard the results anyway because of complex arguments. This test-retest exercise test has potential for circumventing the whole debate.

First the test is 100% objective. It does not rely on patients complaints, what disability insurance companies call “moans and groans”. Effort can be assessed and CFS subjects can be shown to give adequate effort. The results are showing a marked drop in the anaerobic threshold. This is the level that cells convert from oxygen metabolism to anaerobic (no oxygen) metabolism. Normal, lazy, and crazy persons cannot affect their anaerobic threshold. But persons with ME/CFS have a demonstrable defect, probably in the area of energy generation in the mitochondria of individual cells.

There will be more of this over the next few years, as it could help define subgroups, and may point to severity and prognosis. In my opinion, disability companies have cancelled disability payments for thousands of persons who they claim are only “faking” disability. I know one disabled mother who lived in the back of a Chevrolet. Now we can prove that the disability of ME/CFS is very real.

A note of caution. The test on the second day makes people feel quite ill. We will be attempting some methods of making the recovery more comfortable for patients with severe illness.

Advocacy

It is my hope that some energy will be spent on testing and encouraging the new pediatric diagnostic criteria. To this end I would be willing to speak at gatherings of school nurses or school physicians, such as an annual state educational meeting. One way to reach pediatricians is through practical application of these criteria in children or adolescents who are having difficulty attending school. If you have a child or adolescent in this position, you might be able to help arrange an educational meeting via the school nurse at your school. If I could not do such a lecture, I can communicate to the other members of our committee that developed the criteria. If there are proposals to do such a lecture, please call Debbie at 585-765-2060.

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