Nova South Eastern

2015 Patient Conference

On Saturday, February 7, 2015 the annual patient conference has been held at The Rose and **Alfred Miniaci** Performing Arts Center on the main campus of NSE in Davie. Florida

The theme of the 2015 Patient Conference was *Cellular Energy and its Impact on Health.* The event was open to the public and also available to watch via internet, to individuals and families with complex neuro immune disorders.

In addition to the conference a Meet and Greet has been hosted with the speakers prior to the conference for an additional donation. This pre-conference event allowed attendees to interact with the guest speakers.

Speakers and their subjects were:

Gordon Broderick, Ph.D. "Modelling Exercise Dynamics to Restore Immune Signaling in ME/CFS"

Travis Craddock, Ph.D. "Virtual You: Modelling the Role of Homeostatic Drive in the Perpetuation of Chronic Illness"

Richard Deth, Ph.D. "Importance of Antioxidant and Methylation Status in Fatiguing Illnesses" ,

Jon Kaiser, M.D. "Mitochondrial Medicine and ME/CFS"

Lisa Dorfman, M.S., R.D., CSSD, LMHC, FAND "Practical Nutrition Strategies for Acheiving Optimal Health"

Thoughts on the 2015 INIM Patient Seminar - G. Broderick.

As always it was wonderful to see so many patients on February 7 make what is for most a difficult trip to come and spend time with our research team on the campus of Nova Southeastern University, now home to the Institute for Neuroimmune Medicine.

In addition to the close to 100 individuals who attended in person, the seminar was webcast and viewed at over 240 locations spread across over 100 cities in 10 countries. I cannot emphasize enough how inspiring these events are for those of us who as laboratory researchers have few if any opportunities to interact with the very people we are trying to help.

A brilliant example of this is our chief programmer for high-performance computing, **Mark Rice**. For a computer scientist like **Mark**, who is usually tucked away in the largely sterile spaces occupied by rows upon rows of computer servers, the chance to meet patients is always a powerful experience.

When **Dr. Craddock** developed laryngitis, **Mark** delivered **Dr. Craddock**'s talk to an audience of over 50 patients attending in person and over 200 who attended by webcast. Where else would a computer scientist be made to feel so welcome in what is essentially a clinical conference?

Mark is a key member of our growing computational biology team that is busy harnessing the horsepower of Big Computing in an attempt to identify minimally invasive yet maximally effective treatment protocols for delivering lasting relief to ME/CFS sufferers.

The first 2 talks prepared by myself and **Dr. Travis Craddock** with the assistance of **Mr. Rice** were directed at describing our two-pronged research approach. In the first talk we describe the first research stream where we are focused on extracting regulatory imbalances that characteristic ME/CFS from the molecular and cellular data that we collect experimentally.

Because our ability to measure and observe immune and endocrine responses is limited to a rather narrow physiologically safe window we have to integrate experimental observations with a broader knowledge base.

This gave rise to the second talk where we described the second concurrent research effort where we are extracting those relationships that cannot be easily observed experimentally from the considerable body of literature documenting our basic theoretical knowledge of human physiology, biochemistry and biophysics.

This knowledge is used to portray human regulatory physiology as electrical circuits that can then be used to assess how the body's own homeostatic drive might have been hijacked into stabilizing the illness and perhaps even resisting therapy. Both data driven and theory driven models are now being integrated to provide a more complete picture of how well coordinated medical interventions might be used to escape this complex persistent illness.

The next two speakers **Dr. Deth** and **Dr. Kaiser** delivered a very insightful overview of the cell's "lungs", or mitochondria, might be under siege from oxidative stress leading to widespread ramifications. As a biochemist **Dr. Deth** explained in very accessible terms the role of the key antioxidant glutathione in protecting the cellular machinery from damage by the very by-products of its own internal power generating station.

In particular he outlined how the fluid changes made by the cell to its own DNA in response to toxic or other environmental insults through a process called epigenetic regulation might be affected by and involved in curtailing the cell's energy production, in particular in the brain.

He drew on his broad knowledge in other illnesses and also pointed to recent research from the **Shungu group** at **Columbia University** showing increased oxidative species and decreased anti-oxidative species in ventricular spaces of the ME/CFS brain, a condition that correlated closely with illness severity. Building on the basic biochemistry described by **Dr. Deth**, **Dr. Kaiser** brought the basic science into the clinical space.

He went on to describe how his decades of work in HIV and other illnesses where mitochondria are under attack prompted him to search for pharmacologic interventions to rescue the cell from this oxidative onslaught. He was successful in partnering with the pharmaceutical industry to launch rigorous clinical trials focused on harnessing this glutathione and cysteine chemistry to produce significant improvement in several patient populations where mitochondrial dysfunction played a role. Interestingly, **Dr. Kaiser** found that the true protective and restorative potential of these antioxidants was only attained when they were administered jointly with low doses of a stimulant.

This finding of combination therapy involving more than one agent is very consistent with our group's simulations and speaks to the body's highly integrated control mechanisms. The last speaker, a nutritionist, celebrated author and Olympic coach, **Lisa Dorfman** emphasized how any treatment had to be integrated into the broader context of a healthy lifestyle.

Minimizing insults and aggravating factors, integrating carefully designed exercise and improving nutrition are all ingredients for managing illness and improving quality of life.

This was not a boot camp lecture, far from it. **Lisa** punctuated her talk with very practical and pragmatic things that we can do in our homes and in our lives right now to take real and sustainable steps forward, all this with a very conscious focus on the challenges of ME/CFS.

Taken together the seminar integrated basic science with clinical care and lifestyle management in what I hope the audience found to be a well-rounded program. As with any complex illness these multiple elements will be needed if we are to deliver effective care.