

Wetenschap voor Patiënten (Science to patients)

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Webinar 55: Symptoms of ME and treatments

Prof. Leonard Jason. Broadcast October 21th 2014

What is the role of the nervous system in ME?

I think that there is evidence that the nervous system is aberrant in patients with this illness. Certainly some of the work of Alan Light and Kathy Light at the University of Utah suggested that when one puts individuals on some type of exercise with submaximal challenge, one does see some of these types of genetic markers. I do think that there are nervous system domains that patients can have significant problems in. And I think that they are directly implicated in this particular illness.

What we see with most patients is a sympathetic dominance over the parasympathetic system in a sense that their body is 'tuned up'. We often see the symptom called 'being wired'. That's a very common description of patients. They are exhausted but they are still wired.

So in a sense their system is upregulated and I think everything we can do to help patients to downregulate that system is healthy. It's very interesting that lots of the pharmacological things people at times try, including Klonopin and similar things seem to begin to help to downregulate the system. I do think there's an upregulated system in many patients.

What is the role of the blood circulation in ME?

Many patients with ME have a supply of blood that is lower than in healthy people. And when they challenge their body they suffer so-called orthostatic stress when they stand up. They often don't have enough blood flowing to their brain. Individuals sometimes feel they are fainting and they don't feel well. That's because they're not getting enough blood to flow from their bodies up to their brain when they stand up. There seem to be some major circulatory issues among patients. Orthostatic intolerance is one manifestation of that.

How do you measure post-exertional malaise?

Post-exertional malaise can be measured by asking the right questions on self-reported questionnaires as well as by exercise challenges, whether by letting people exercise on bicycles for ten or eleven minutes, or even up to twenty minutes in a submaximal challenge. I think it's important to look at both what people say as well as what people do in a laboratory setting, to bring the best of both together to understand this complex symptom called post-exertional malaise.

What is the role of infections in ME?

Many patients begin to get symptoms after some viral infection. So it does seem certain, as in some samples up to seventy percent of people report having had some type of viral infection. Ultimately the best way we are going to understand the role of these types of infections is longitudinal prospective studies.

An example is that in Chicago we're currently involved with Ben Katz, who's at Childrens Northwestern. Over time we're going to follow thousands of college students who are healthy, to see which ones develop mono and which ones recover and don't recover. That's the best way for us to be able to identify whether a particular virus or a other types of things might be both involved in etiology as well as in maintenance of an illness.

Are there any markers for ME?

About markers for ME... I think that we could say we are beginning to identify some of them and in the future I think there will be many others. There certainly are cortisol difficulties. It seems that people who have a lesser increase in cortisol in the morning might be a very good marker. Natural killer cell activity has been talked about in a number of review articles. There might also be subgroups of individuals who have other types of markers. In the future we will hopefully be able to discover many more of these and will be able to get them across laboratories.

But again, if you're going to find markers, it's only going to be if you have the same types of patients in different settings. That's why the case definition is so important. We have to identify the same people in different places if we are ever going to find consistent biological markers. That's so important because if you don't find consistent biological markers, it's very easy for people to assume it's a psychogenic, psychiatric illness as opposed to a biological one.