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On Friday June 6th 2014 Prof. dr. Julia Newton answered questions in a chatwing-session. These are the Q&A of this session.

Q: In your first college, number 43, you mention there are problems with the acid in muscles. Does this mean there is too much acid or does the acid change of quality? I ask about the quality because the experience of having ME- muscle pain is so different from having normal muscle pain.

A: We have shown that there is an increase in acid in muscles both on magnetic resonance spectroscopy whilst people with ME have exercised in the scanner - but also we have reproduced these findings in muscle cells taken directly from patients with ME.

Q: About the name ME: have the inflammations in the brain been proven or not at all?

A: inflammation in the brain is interesting and there is some controversy whether it is present in ME or not. Some scans suggest it is there - but more studies are needed to be sure.

Q: Why do those problems with acid occur??

A: Good question - we think the problems with acid might occur because of disordered muscle metabolism within the cells perhaps mitochondrial disorder. The severity of acid accumulation associates with autonomic dysfunction which might suggest that there are also problems of how the transporters get rid of acid (these transporters are controlled by the autonomic nervous system) or because of problems with vascular run off from exercising muscle.

Q: Patients with ME often also complain about restless legs. What is 'restless legs'? What is the difference between and resemblance with ME-muscle pain? Why is the combination ME with restless legs to be seen so often?

A: Restless legs is a recognized neurological condition for which there are licensed medications. So this is an important problem to identify and treat in patients with ME - because it can cause sleep problems (which can themselves be associated with fatigue). The post exertional malaise and muscle pain that is typical of ME is different I think.

Q: Do you think neurotransmitters could be the (main) problem? Or rather, do you agree with me they are?

A: I agree abnormalities of neurotransmitters could be a problem - but I am not sure there is enough evidence yet to suggest they are THE answer. So I suppose I half agree. A lot of my work focusses upon muscle function, and we have now identified significant abnormalities in ME (and other fatigue associated diseases). So there are clearly lots of different things going on. Or perhaps more likely a number of different diseases.

Q: In webinar 44 you mention that ME patients often have problems with the executive functions. Is it coincidental or related that in case of autism there are also often problems with the executive functions?

A: Not sure about the autism question. I have to admit that I don't know a lot about autism so would be guided by you.

Q: Why does PEM at times occur later or postponed? Is that explicable? Does it have to do with the sympathetic nervous system?

A: I suppose it depends upon what the activity is that underpins the symptom. There are often delays in muscle pain after exercise even in those without ME.

Q: You start from the assumption that problems with cognitive functions and memory relate to blood pressure. If it is possible to restore blood flow, will the cognitive problems be solved then? Or is ongoing damage being caused?

A: This is a trial I would love to do. It is certainly an important question and until we do the study it is difficult to answer. We certainly know that the muscle acid accumulation is reversible in the laboratory - so it might also be that the cognitive abnormalities (if these are generic) are also reversible. But you are correct one way to answer that it is to see whether cognition improves if blood pressure is increased.

Q: Can pregnancy make the whole ME worse? The pain in the muscles? The nervous system?

A: Not sure, there is not much evidence in the medical literature to help us understand what happens to people with ME who are pregnant. In my clinic some people tell me that they feel better whilst pregnant and some not.

Q: You talked about headache that is caused by joint dysfunction and that there was a special treatment for this type of headache. Can you tell us more about this special treatment and does it involve medication? For the record: I sometimes have this type of headache, it involves my joint muscles and I use oxazepam to relax them. It helps if I don't use it too much, but I want to know if there are alternative treatments.

A: The joint problem is called temporomandibular joint dysfunction. It is known to be commoner in association with autonomic dysfunction - something we know is commoner in ME. In a non-ME setting gabapentin, pregabalin and acupuncture have been shown to be of some benefit. There are no specific trials yet in ME.

Q: If problems with cognitive functions relate to problems with the blood flow, why aren't they more constant? Isn't the blood flow a constant factor?

A: Blood flow is not a constant factor - it is constantly changing, controlled by the autonomic nervous system. So if we have a big meal the blood flow to the gut increases to digest that meal. If we stand up the blood flow increases to our legs, away from our central circulation. The human body is designed to try and preserve brain blood flow (and volume) at all costs. So the brain circulation has a special additional control system called 'cerebral autoregulation'. We think that this extra control system might be a problem in ME.

There have been anecdotal reports that if people receive IV fluid they feel better - in our current study we have measured blood volume and are looking at the results at the minute.