

Wetenschap voor Patiënten (Science to patients)

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On Friday July 3rd 2014 Prof. dr. Julia Newton answered questions in a chatwing-session. These are the Q&A of this session.

Q: Is CFS hereditary? My mother has the disease, and she says that it is hereditary. She told me that it is like a little ball within your body and it burst suddenly. Now I have a problem in that I want children. But my husband and I have reached the decision that if it is hereditary, we will not have children. I show no symptoms of the disease. Hopefully you can help me out.

A: What do you mean by CFS ? Do you mean ME ? There is no gene been shown to be associated with ME. So although there is some evidence that it runs in families, it isn't genetic

Q: My mom told me that it's possible I have it and give it on to my children.

A: There is no current evidence that it is passed from parent to child. If you have no symptoms then it is important not to live your life worrying about whether you will develop the disease.

Q: Does that mean it is absolutely safe, or that you can't tell?

A: There is no evidence and from studies it is unlikely that the precipitating factor is primarily a gene abnormality.

Q: Can you say something about paralysis in ME? Is it is related to autonomic dysfunction? Have you worked with anyone who experiences muscle paralysis with ME?

A: Muscle paralysis is not common in the patients that I see. If I had a patient with paralysis I would ask one of my neurology colleagues to see them.

Q: When you refer such cases to a neurologist, what explanations do you get back?

A: Clonus or myoclonic jerks sometimes - restless legs syndrome.

Q: Can I deduct from your answer that spasms in ME (and I hear quite some people complaining about them) aren't caused by acid accumulation?

A: I suspect not.

Q: How can you tell if a POTS patient also has CFS since the symptoms of POTS are a lot like CFS?

A: By measuring their heart rate lying down and when they stand up. If it increases by more than 30 beats per minute or to about 120 within 10 minutes of standing , that would be consistent with a diagnosis of POTS. So if you simply consider the symptoms and don't do the proper measurement you can miss it.

Q: But how do you know if it's only POTS or both CFS and POTS? Since not everyone with POTS also has CFS. Or do you think differently about that?

A: It is difficult. Some people would argue that by having CFS you can't have POTS and vice versa. But I generally think about it as CFS with a POTS phenotype.

Q: In webinar 46 you mention that a deficiency of certain proteins, which possibly give problems in the metabolic chain within the cells, might be modulated by medication. Do those medicines already exist and do you have results from experiments with them?

A: We have done some experiments in the lab (funded by Action for ME) where we are adding different proteins to exercising muscle cells to see whether these proteins might improve how they work. At the moment we are still deciding what might be the best treatment to then consider in clinical trials.

Q: About the two phenotypes: are all patients in this experiment diagnosed with ME? And do they all suffer from PENE, or just the group that gets worse after exercise?

A: There was no difference between the two phenotypes. They all have CFS and all had the same amount of pain after exercising. They were equally fatigued.

Q: Is there an interaction between adrenaline and lactic acid?

A: There is a suggestion that some of the transporters that remove acid from muscle cells are modulated by the autonomic nervous system.

Q: Do you know anything about the spasms very severe ME-patients have? I have them when I am very exhausted, every day, together with a difficulty to pronounce words. They make the exhaustion only worse. Or is this symptom not studied (yet) because lighter cases don't have it, like paralysis?

A: Spasms are unusual. Not something that is well understood.

Q: After being ill for more than 5 years, my weight has steadily grown with more than 10 kilos and I hate it! It is tempting to start a low caloric diet with few carbohydrates. But of course I know that for people who are not ill those diets already give problems with the muscles. Is it for ME-patients even worse to follow such a diet, given the problems with their muscles? If it is, is there another diet that you would suggest specifically for ME patients?

A: I would consider trying it if you feel you need to for overall health benefits and see how it goes. Clearly stop it if it doesn't suit you.

Q: What do you think of rituximab? Is it safe (enough)?

A: We are currently involved in a rituximab trial in a chronic disease called PBC. The consent form and patient information sheet is very long because there are a lot of reported complications recognized with the use of rituximab. I think it needs to be used in very carefully selected patients with appropriate monitoring. So I think well performed clinical trials are important if rituximab is to be used in ME.

I think our current trial will provide some evidence for the potential benefits. This trial for 76 patients (50% get the rituximab) has cost over £1million with the drug costing over £250.000 alone.

Q: How is the trial going till so far?

V: It is proving more difficult to recruit participants than we expected. But it is otherwise going ok.

Q: You'd think people would be lining up. Any reason why they aren't?

A: It involves quite a lot of visits to the hospital, rituximab has side effects, it involves an infusion of medicine and only 50% get the active drug.

Q: Lately I saw an advertisement for a training for patients with ME, depression, burn-out, anxiety etc. Patients will be taught techniques to influence the amygdala in order to get out of the situation of chronic stress that is due to being patients with a chronic disease, according to the therapists. Do you consider this as a useful kind of therapy for ME patients? Or is it wishful thinking?

A: I am not sure about the evidence for such a treatment. Is it published ? Have there been properly conducted clinical trials to underpin the evidence behind its use ?

Q: In the website of the therapist they claim the therapy to be based on scientific evidence. But I can't find the articles where it is all based on.

A: ?????? Say no more.

Q: A few years back there was a lecture during the Invest in ME Conference about this amygdala training by the developer.

A: I would be interested to know what diseases it has been used in and what evidence there is for its benefit.

Q: What do you think about a lot of ME patients that test positive for Lyme disease? Do you test your patients for Lyme when they come in?

A: We don't test routinely.

Q: Muscle cells of ME patients are low in AMPK. Could acadesine correct this and would this be helpful for ME patients?

A: We are doing some more experiments, so we can include this to see.

Q: About oversensitivity of the senses with ME-patients: could the statement that the senses of ME/cfs patients become oversensitive be reversed in: can highly sensitive persons (overreacting on all sensitive impulses) have a predisposition to get ME, as they are more prone to stress and influences on the senses and the nervous system? If so, is any research in that direction being done?

A: I'm not sure whether there is any research in this area. But it is a good question: is it that people with oversensitivity for some reason have a predisposition to ME ?

Q: It is a hot item presently: Lyme. A lot of people are testing positive on Borrelia and co-infections. Is that an eye-catcher in your practice as well? Is it an exclusion criterium for your research?

A: Not currently. Who is testing and with what ? It is important that it is a robust and validated assay.

Q: Most are being tested in Augsburg. When Elisa-bloodtests show no Borrelia in the blood, one is not considered to suffer from Lyme. But that appears to be a very shallow test in case the bacteria have retreated to other parts of the body.

A: Is there evidence that Borrelia retreats to other parts of the body? I don't know the literature.

Q: De Meirleir and other docs are testing people with LTT Melisa in Augsburg. Besides that Lyme is also a clinical diagnosis. There are a lot of patients who are responding to antibiotics or other Lyme treatments, although not everyone gets better in it.

A: They need to make sure they publish it.