

## Wetenschap voor Patiënten (Science to patients)

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### Webinar 49: ME and the future

**Prof. Julia Newton. Broadcast August 5<sup>th</sup> 2014**

#### **In which field do you expect biomarkers to pop up?**

Biomarkers are what we all consider to be the holy grail. Having something that we can measure in the blood or use as a diagnostic tool to help us identify patients with ME or different phenotypes within this umbrella diagnosis of ME are some things we all strive for. At the moment we have a MRC funded project trying to identify a biomarker for fatigue. We're using patients with a condition called Sjögren's where fatigue is very common, to try and look for a fatigue fingerprint using immunological markers. We're then going to take that fingerprint and apply it in patients with ME to see whether or not we can identify specific abnormalities that have potential to be an immunological biomarker in patients with ME under the fatigue associated diseases.

But of course for somebody like me who's interested in the autonomic nervous system, biomarkers aren't isolated to the blood. We've recently published a very small study suggesting that actually some of the many parameters that we collect, when we're assessing the autonomic nervous system in patients with ME, might also have the potential to be a diagnostic biomarker. So I think we shouldn't isolate ourselves to looking for biomarkers just necessarily in the blood. There are lots of different things that individually or combined together might help us understand ME more fully.

#### **Which hopeful studies are going on presently?**

At the moment we've got a range of studies going on here in Newcastle. We've got two large MRC funded projects which count for over a million pounds of grand funding from the Medical Research Council. One of these is to look for a fatigue biomarker using immunological samples. We're also doing a study where we're looking at understanding autonomic dysfunction and its associated cognitive consequences. In that study we're recruiting over eighty patients with ME/CFS to come in and have a whole range of different investigations including MRI scans and HPA axis tests, autonomic function cognitive tests, etc. That involves seven visits to the hospital, so it's quite a major undertaking for participants. We've also got a PhD student Gina, who's funded by Action for ME, and she's looking at our laboratory muscle experiments.

Looking whether we can come up with a drug that would reverse some of the acid that we've seen accumulate in the muscles of patients with ME. We've also got a PhD student, Luke, who's looking at the overlap between migraine, ME and temporomandibular joint dysfunction, and he's working with me and a colleague, doctor Justin Durham, looking at symptoms and the overlap between those symptoms. We've also got a very close

collaboration with colleagues at Northumbria University, where we're doing some experiments looking at sleep.

The quality of sleep, length of sleep and a range different sleep parameters. Those studies have been funded by Action for ME and the ME Association. ME research UK which is one of the other charities in the UK have also been very generous to us, helping us develop additional priming projects looking at MRI technologies and looking at something called 'systems medicine' to try and understand the complexity of all the results that we get and how all these different systems interrelate with each other.

### **What's your view on cooperative efforts like OMI, Simmaron, Mt.Sinai, Griffith and CMRC**

It's really important that we form strong collaborations between clinicians and researchers working in this field. The way that we're going to improve our understanding of this disease and rapidly lead to better treatments and greater understanding is if we have a collective approach. So working collaboratively I see as a huge asset to move in this field forward. The other thing I think is really important is that we don't look at ME in isolation.

That we actually learn things from other diseases where fatigue might be a problem. For example, at the moment in Newcastle we have a trial of Rituximab in patients with primary biliary cirrhosis, that has fatigue as an endpoint. So it's the first trial specifically targeting fatigue in primary biliary cirrhosis with Rituximab as the intervention. I firmly believe that the lessons that we learn from this trial will have direct relevance to our understanding of fatigue in other diseases such as ME. And will allow us to fast-track treatments such as Rituximab very quickly toward the fatigue associated diseases.

### **How can ME become part of the tuition of medical students?**

What's really important if we're going to understand ME is to make sure that people, particularly healthcare professionals such as doctors, nurses, allied health professionals understand what ME is. Understand the complexities of diagnosing and managing this disease, and recognize how important it is for us to do future research. Influencing these professional groups at a very early stage is really important.

Recently we've had two things here in Newcastle, which have been very exciting, in that myself and my colleague professor Jason Ellis did something called mini medical school, where 500 sixth-formers came in to the medical school. The sixth-formers were wanting to go to medical school and so we're gaining some experience of what it is like to be a medical student. Jason and I lectured to them about fatigue and sleep problems, for a couple of hours one evening. The atmosphere and the vibe and enthusiasm from these medical students, sorry sixth-formers, was really infectious.

The other thing that I've done just a week ago, was actually to speak to the fourth-year medical students in the medical school. As happens with these things I went along feeling a bit, you know, reluctant to do this lecture to 350 medical students. But was actually blown away by their enthusiasm and the sensible and appropriate questions that they asked me at the end of my lecture. As a result I now had emails from a number of them wanting to come and work with my group over the summer, during their summer vacation. So that they can learn a bit more about what it is to have fatigue and ME specifically.

So I think engaging with younger age groups particularly those who are expressing an interest in becoming a clinician, whether that be a doctor or a nurse or an allied health professional is really important if we're to help them understand the importance of this disease. What I will often say to medical students when I speak to them is: "When I sat in your seat as a medical student 20+ years ago, and I was taught that peptic ulcer disease was arose because of stress. And now 20+ years later we understand that peptic ulcer disease doesn't arise because of stress. It arises because of a bacteria and that there is now a multi-million pound industry eradicating *Helicobacter pylori* in people who've had a peptic ulcer. And if our understanding of a disease can change so dramatically in just over twenty years, imagine if we all work together to understand ME how far we could go in a similar length of time".