

## Wetenschap voor Patiënten (Science to patients)

It is permitted to disseminate all transcripts within the project Wetenschap voor Patiënten (Science to Patients), under the explicit condition that the source ME/cvs Vereniging, <http://www.me-cvsvereniging.nl/> is clearly mentioned.

### Webinar 57: Future/ teaching about ME

Prof. Leonard Jason. Broadcast November 18<sup>th</sup> 2014

#### **You published about teaching ME/cfs in US medical schools. What were your findings?**

We did an initial study involving medical textbooks. And we found that in the medical textbooks which are used to teach future physicians, ME and CFS were rarely mentioned. And even worse, when they were mentioned they often didn't contain actual information about it. So the basic teaching materials that are being used in our medical colleges are very negligent and often inaccurate. That has to be corrected.

Recently we also did a survey of what does occur in medical colleges in the United States. What we found was again that these topics are underrepresented and that has to change. There has to be more focus on teaching of, application of and research on ME in medical schools. Until that changes, we're not going to have people finishing the medical college who are adequate and providing the coverage that patients need. So this has to be one of the high priority issues that we work on.

#### **You also did this kind of research a few years ago. Have there been changes since then?**

The research that we are currently doing, implies our constant learning from the past. We're trying to integrate the type work for example with computers and people who understand artificial intelligence. So that we can use not just the consensus way of making a case definition, but we can use the best sciences in things like data mining and artificial intelligence, to come up with case definitions that might be more specific and accurate and sensitive. That's some of the work we're currently doing and we're also again trying to look at different ways of using multivariate and more complex modelling, to have empiric ways of making decisions in understanding how systems operate. As opposed to try and have just the consensus way of making case definitions or scientific pronouncements.

We think that our research has made a difference. In the nineteen nineties ME was really considered to be a relatively rare disorder, affecting the yuppies and called the yuppie flu at the time our data came out in the late nineteen nineties and early two thousands. The prevalence estimates that are now being used by the federal government indicate that they estimate it closer to ours, a million people having this illness. So we've been able to battle the misperception myth that this is a rare yuppie flu illness. We now think it's a very significant illness that is not a yuppie flu, which affects many more people than we previously thought.

In addition our research has challenged the term cfs and we have championed trying to get alternative terms. There's a number of organisations that are now using both ME/cfs and ME

and I think our research has helped to contribute to that shift. Finally there's our case definition research of comparing and contrasting different case definitions and using empirical methods rather than consensus methods to think about what are the core features and how to measure those core features. We think we'll continue to make important contributions to the debate on the case definitions that is currently going on.

### **Does DePaul University/Rosalind Franklin University teach medical students about ME?**

The DePaul University doesn't have a medical school. There's been some talk about maybe some type of alliance with Rosalind Franklin but it is in the very early stages. We have made some efforts to begin to collaborate with people at Rosalind Franklin, but again those are early efforts at this point.

We do think that multidisciplinary efforts are important. So we have an epigeneticist in Iowa that we're working with, we have an immunologist within the nursing department at DePaul that we're working with, we have a computer science expert in the computer science department that we're working with and we have people in different universities that we collaborate with. It's critical for us to think about multidisciplinary research beyond the particular laboratories of our particular settings. And that is going to be the key to research, whether we have a particular medical school or not.

### **What research are you working on at this moment?**

We have several lines of research that we are focussing on. One is the use of our DePaul symptom questionnaire to gather large databases and we think with these large databases of patients versus controls we'll be able to better understand which symptoms differentiate these groups. We're using very sophisticated, even artificial intelligence techniques that are empirically based rather than consensus based in trying to help us inform the decisions regarding the case definition. In addition we're not just interested in self report issues with our questionnaire. We're also looking at data that involve more physiological, biological measures.

For example, we are now looking at college students and trying to find over time which ones develop mono and which ones don't and which ones recover and which ones don't. And we have blood samples of all those particular college students so that we'll be able to look at what they were like when they were healthy and what happened after they got sick. That type of longitudinal prospective research is critically important.

I might add that we also have an epidemiology study going on with paediatric ME and that's going to be an important kind of lesson for us to also look at the biological as well as the other domains that help us understand what are the risk factors and how many individuals within their youth have this illness. That's something that we'll be working on as well in the future.

### **What other research do you think will be hopeful for the near future?**

I think the most important research that will occur in the future is going to involve multidisciplinary efforts that will bring in people from different disciplines, including computer scientists who have mathematical gifts to help us understand decision trees, so that we can figure out what symptoms might be the best predictors of illness. We might be able to bring in also people from the best of the sciences, the best virologists, epidemiologists, people who understand the autonomic nervous system.

So what we really are looking for is how do we get together people with genetic backgrounds and environmental backgrounds and public health backgrounds to participate in these types of rich multidisciplinary efforts. To understand what we think to be the greatest challenge to medicine today. Because medicine knows how to fix a broken bone, medicine knows how to deal with people who have the flu, medicine knows how to deal with many types of illnesses. What's really a puzzle for people are these complex illnesses and as we get insights into the mechanisms that are involved in complex illnesses like ME, we are going to have a new birth of understanding of what persons have to face and how we can better understand the human condition.

That type of research really needs to have adequate funding. We will one day be able to reinterpret different types of illnesses based on what we learned from people with ME.

At the present time there are many economic challenges to countries. I think these are difficult times for both basic researchers as well as patients. But I have faith and I have hope that over time we will recognise that the greatest medical insights will occur while involving patients with the most complex system issues such as ME. And as we get more scientists and researchers to understand this basic fact, my belief is that we will begin to bring together the best scientists in the world to study what I think is one of the most neglected but most important medical illnesses facing our world.