WBUR Interview with Ronald W. Davis, PhD, for MA Dept Public Health April 2018

DB: I am going to read a little bit of his bio here.

Ron Davis is a Professor of Biochemistry and Genetics at Stanford University and he is also director of the Stanford Genome Technology Center. He is the Director of the CFS Research Center at Stanford and a member of the National Academy of Sciences. He is the Scientific Advisory Board Director of the Open Medicine Foundation. Of course, Dr Davis's son, as you saw in Jen's film, has severe ME.

Ron, thanks so much for being here with us. How is your son?

RD: I think he is getting a bit better because he is shifting his schedule and is waking up earlier.

DB: I hope that he is ok. You just got a $5 million bitcoin donation for the Open Medicine Foundation? Is that right?

RD: We received a substantial number of donations recently and that has caused a great deal of excitement. We are now planning how we are going to use the money. We have to be careful not to use the money on things that are not necessarily going to pay off. There is a lot of strategic planning. Our major effort is to try to develop a biomarker. We actually have four different ones that are showing great promise. One of them is something that we call a nanoneedle. Every CFS patient shows a positive signal in this assay and none of the healthy controls do. That's a better marker so far than seen in any other system. We have three others that we are pursuing. We have less data on them.

DB: From a researcher's perspective, can you tell us what you think is happening in many of the folks who have ME? What do you see physically that is going on? How are you describing it?

RD: Well, I think that it is a systemic disease. We certainly see a hypometabolic reaction. A large number of metabolites are low and Robert Naviaux has done an excellent job. We have also seen a lot of metabolites and we concur with what Robert Naviaux sees. A lot of the lipids are affected in this disease. That is now something that we are pursuing pretty heavily.

We also see a large number of mutations that are probably affecting the patients. Some of them are probably causing some of their symptoms. Every patient has a different collection of mutations. So you can account easily for all the varied symptoms that the patients experience. There is a tendency to want to group these into different categories of the disease. My suspicions are there are as many categories as there are patients and therefore it is not a useful thing to do. We will come up with large studies soon from severely ill patients.

We have a large number of other patients that we are putting together, that is a family study. We look at patients and everybody within the family. Many of these families that we are looking at have multiple ill members but they also have healthy members. Comparing the healthy people within the family with the ill patients has been quite constructive because they share a lot of the same genetics, environment, and diet. I am hoping that will point us in the right direction.

But we do believe that it is some sort of systemic problem probably with some central control circuit. It's a matter of trying to find what is that central control circuit that is messed up in some way. We think there is something going on that locks the patients into this and they can't get out of it. So if we can figure out what that control circuit is then we can figure out our strategy to unlock it. That is our major effort at the moment because that would possibly mean that we don't need to develop a drug. There may be ways to manipulate that central circuit to get people out of the disease. We have one primary circuit that we are looking at, at the moment, we should figure out whether that is right by the end of the summer.

DB: So what would your advice be to a room full of health care professionals here in Boston? What would you tell them as they potentially work with patients who may have the disease?

RD: I think that right now the health care professionals should treat symptoms and listen to the patients. You have to listen clearly to the patients. Patients don't all have the same symptoms. And you need to look at each patient and their symptoms and come up with your own strategy that may help treat that. There are a lot of drugs out there that can modulate these things and hopefully that will work.