Ronald G. Tompkins, MD, ScD | ME/CFS Collaborative Research Center at Harvard

https://www.youtube.com/watch?v=WXWJKotFuNE&list=PLl4AfLZNZEQPxjqF4ojAO3wdCFMeriNBK&index=12

Raeka Aiyar: Welcome back. I hope everybody had a great lunch and it was really nice to see all of the interactions happening between the patients and the researchers. That's one really nice, unique aspect of this event. Welcome back to everyone on livestream, we're very glad to have you here.

Right before we start, for the people who are here, there is a very uniquely folded $20 bill that was found, so if you can describe to me the way in which it was folded then it's yours.

(Audience laughs)

Audience member: Neatly.

Raeka: (Laughs) Keep trying.

Audience member: Acute angles.

Raeka: Acute angles, that's good.

Okay, so we're ready to get started with our afternoon session. Thank you all again for your engagement in the morning session and all of those wonderful questions. We have opened up the question portal again at the URL that was on here before, omf.ngo/question.

I'm happy to welcome our next speaker up, Ron Tompkins from Harvard and MGH. An omber ... Excuse me, a member of the OMF Scientific Advisory Board and a close collaborator of Ron's for many years.

Ronald Davis: Well, I've worked with Ron I guess actually a couple of decades now and it's been really great. Now, don't be fooled by his dress as a physician. He's actually a geek (all laugh), because he came from MIT and that's a requirement to get out.

Anyway, he's worked a lot on trauma and a big trauma study we did with him and there's a lot of similarities between what happens in trauma and sepsis and huge immune reactions and so forth. The hope is that we will maybe learn something from that, because there's a verily massive database of that ton of data and maybe we can use it to understand. Because a lot of times the body reacts very similarly it with different types of insults.

It's a great pleasure to have him here and he's gonna run the the other center on the other coast, the Stanford of the east.

Ron Tompkins: Stanford.

(All laugh)

Yeah, yeah, yeah. Thank you very much, Ron. We've known each other and worked very productively for, I guess, two decades now. He was very kind to add so much in the way of genomics and computation to our studies and such that I'm eternally grateful for our relationship.

I am totally new to this field and I just want to say that I have been welcomed by the investigators and also the community and their caretakers. I would hope to add something meaningful to your struggle with this disease.

I'm embarrassed as a doctor. Part of me is doctor, part of me is an MIT chemical engineer, but my doctor side is very embarrassed by the way that my community generally responds to a disease they do not understand and for which understanding what treatments might be useful is really hard. So many of the doctors these days are simply going by protocols and if you don't meet that protocol, for which there is none, it seems to me in ME that you can't possibly have a disease. I just find that ridiculous.

Our group has spent a very long time understanding the human response to an injury that was serious enough to kill you. A 20% mortality rate. As Ron mentioned there're a great deal of findings that are in spades in the human response to such an injury that, to a lesser degree, are also shared in the disease of ME.

We know a great deal about inflammation, immunity, and metabolism and I would hope to be able to add some of those insights to better understand those abnormal features in ME. That's my reason for being here.

I learned a lot being on the Scientific Advisory Board of Open Medicine Foundation and as we were going along the Harvard of the west (audience laughs) I like to think. We have had such a productive relationship over such a long period that we would be able to rejuvenate that and continue that in the field of ME. That's certainly our intent.

Harvard cares a great deal about its name and so using it loosely is a very touchy subject, so what we call this center, it is compromise right at the moment, but is ME/CSF Collaborative Research Center at Harvard.

What it is is they're a group of clinicians at Harvard who have contributed and continue to contribute substantially in the field of ME, and I'll point them out, but also there are superb investigators with unique resources that could easily be recruited and are willing to be recruited into highly resolved studies in the field of ME.

We have 12 investigators from Mass General, we have a true expert in the field of sleep, Dr. Mulligan at the Beth Israel, and we have two investigators David Systrom and a name that should be well-known here is Tony Komarov. All of them are enthusiastically

interested in our common initiative at this point and hopefully is a well-funded center sometime in the very near future.

Because it's very important to have proper controls, we have close collaborators also at the University of Birmingham. Janet Lord is Chair of the Department of Immunology there. She's very interested in innate immunity, that plays a real role in ME, and she's quite interested. She's head of a Center for Aging and Inflammation.

Two close colleagues at the University of Nottingham, who are excellent physiologists and classical physiologists studying metabolism, are very enthusiastically interested in participation.

There's been great progress in the UK. I think part of a very long discussion at Parliament in early summer, in June, has had an impact on the MRC. The MRC has put out an announcement for a request for proposals and we're gonna engage and participate in that request. I think that would be wonderful.

Studying normal seems to be more straightforward. I don't know what it is like in California, but I can tell you studying normal in any kind of invasive way at Harvard is just not gonna happen, but in the UK it seems to really little bit more straightforward. They are superb scientists and I'm delighted to be working with them on that. That's a very important control.

Lastly, a group that is, in my opinion, the very best high-throughput proteomics people in the entire world for that matter, are very interested to participate with us. We have also, Ron and I, have worked with them for almost the whole time and they have been absolutely superb. They're interested in fatigue and muscle metabolism. We are just delighted to have them join us. We're beginning here.

How does this advance? Oh, I'm sorry.

Your first question might be what do we intend to do. It's a staged process and our intent at the moment is conduct clinical science mechanistic studies with a very high priority. A lot of this depends on the staging of funding. These things are are gated by that. Our initial research focused to discover particularly the recovery mechanisms that occur in ME that is, in some fashion, dysregulated, creating this post exertional malaise syndrome.

By deeply analyzing what is happening in muscle biopsies, in a way that never has ever been done in any way close in the past, we think has some likelihood.

Another area where we offer some real unique expertise is in neuroimaging. There are many technologies that have been developed in Martinos Center and other MRI, magnetic resonance, and ... MRI and PET have come from Mass General. There are very unique opportunities for neuroimaging and we've recruited quite a number of individuals

there who are willing and interested and actually currently conducting research along these lines.

We just feel that well-characterized patients studied in the very best way possible can add new information for our field and help us at least to come closer to a biomarker, with our intent ultimately new therapies. That's really our intent.

As funding proceeds we would love to develop a clinical trials network for multicenter clinical trials and that would be ... MGH does that very often and we would be delighted. Those are very expensive endeavors, but that was also one of our intent.

Our real interest is developing new therapeutics for this field and we would hope that we would be able to do that.

Thank you very much.

(Audience applause)