

Ronald W. Davis, PhD - Interview

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Hello, I'm Ronald Davis, a professor of genetics and biochemistry at Stanford University. I'm also the Director of the Stanford Genome Technology Center which develops a lot of the technology for the Genome Project. I'm also the Chair of the Scientific Advisory Committee for the Open Medicine Foundation which supports Chronic Fatigue Syndrome research. I'm here to talk about Chronic Fatigue Syndrome. It's a really devastating disease. My son is struck with it. He's very severe so this illustrates a little bit how bad this disease can be which is largely unknown. In his case, he's totally bed-bound. He cannot eat, so we feed him by a tube into the top of his intestine, going through his stomach wall. He can't swallow so we have to give him fluid. He has a line into his chest which goes into his heart. He also can't talk. He cannot read. He cannot look at numbers. He cannot look at letters. He cannot look at us because it's too stressful. If we are in the room, he has to cover his eyes. He's super sound sensitive which means we can't talk to him and we can't even make any small noises. He's also super smell sensitive so we can't cook in our kitchen in the house because the smell will really bother him.

This is not an unusual case. There are literally thousands of people all over the world that are this severe. Many of them are so severe that they choose suicide. It is very common to have a patient commit suicide which is really unfortunate. In my son's case, he had a number of friends before he got super sick and was corresponding with them on the internet and a couple of them committed suicide which really bothered him. This is a really devastating disease. It probably affects around one percent of the population. That's a rough estimate. I think many of the estimates are under-reporting it because there's not an easy way to figure out how many people have this. They frequently don't go to doctors. They often don't have any insurance coverage. There's no easy way to assess it. You can get a little bit of an idea of the less severe patients. I do know that the CDC made phone calls to households on landlines to try to determine this. But of course, an ME/CFS patient will never answer the phone. So it's really tough to get an accurate number. It's also really expensive. They often require, if very severe, a caretaker. Some of them require 24/7 care and it's not uncommon, even with insurance coverage, to spend over a hundred thousand dollars a year to take care of one of these patients.

Now the disease itself affects multiple organ systems. It does not seem to have a major effect on the heart or the liver or the kidneys which is what physicians often look at. It's not an organ type disease. It's systemic. It affects the brain. It affects the immune system. It affects the digestive system. There are many, many symptoms that come from those. Because it affects the brain, it's been viewed in the past as a psychosomatic disease. They simply believe they're sick. That's when they measure things like cholesterol level, it's perfectly normal. Now I've described my son to you. If you do all of the things that a doctor normally will do when they look at a patient, all of those things look normal. That's because those systems are not particularly affected but many, many other things are.

So the patients have been ignored for a very long time. There's very little funding and that's a serious problem. This disease has been ignored for many, many years. It's something people should be a little scared of because you can come down with this disease at almost any time of your life, except when you're particularly young. So the incidence really starts in the late teenage years. One of the common things is an Epstein-Barr virus infection which leads to a disease called mononucleosis. One study found

that ten percent of students that come down with mononucleosis convert to chronic fatigue syndrome. With our current level of understanding of this disease, if you get chronic fatigue syndrome or ME/CFS, your life as you know it, it's over. That is really sad because it hits such people at the prime of their life. There's a lot of things that can cause this disease. Any stressor can cause this disease. There are many types of viral infections that can cause it. In Australia, the Ross River virus infections can cause it. It can also be caused by giardia. That occurred, an epidemic occurred, in Norway. But many other types of stressors can cause it, like an auto accident, a surgery, childbirth, anything that is a major body stressor can cause this disease. So everybody, as far as we can tell, is vulnerable to this and there's nothing you can do to really protect yourself.

So what is needed is research funding and that is needed throughout the world. I really urge government and private donors to find high level, high quality researchers and support them. This is not an easy disease to work on. There are a lot of other things that are much easier to work on. I think we need to induce people to study this disease. It's been unknown for a very long time. It's been felt it's not a very serious disease but in fact it's an extremely serious disease. There are a number of physicians that treat AIDS patients as well as ME/CFS patients and they all claim if they had a choice they would take AIDS over ME/CFS.

I would particularly appeal to anyone that's in the high tech field that has earned a great deal of money that in fact you can make a major contribution by attacking this disease. Because it has so little funding, even modest donations will actually make a fairly large difference. We really need to have a number of sites that are well-funded so they could also work together. So our model really is not to just focus on collecting some data and publishing it but in fact to really focus on what can happen to make the patients better or also find what is the origin of this disease. What's the fundamental problem? If we can do that, we might actually have a chance of curing the patients. I think a modest amount of funding would help tremendously but if you are very serious about it – when I was doing the Genome Project, we had funding levels of around ten million dollars a year, which is actually a very effective way to run a laboratory. Because what you do at that level of funding is you recruit high level, high quality people that are [from] multiple disciplines, like electrical engineering, computer science, a degree in medicine, biochemists, geneticists, cell biologists, and just do the whole gamut of disciplines. So when you attack a problem, you can bring together experts in those particular areas to try to address it.

*Thank you to Lisa for transcribing this video.*