Dr. Friedman - The future for CFS Research and Treatment, Encouraging news from the IACFS/ME Conference in Ottawa

The following information has been kindly approved for reprint by Jane Clout of www.mecfsforums.com following a radio interview entitled "disrespect".

04:00 Ken: "In the United States there was just a very recent - I'm going to use the term battle -with regard to the ICD because the US government was going to place Chronic Fatigue Syndrome as a somatoform disorder as opposed to maintaining it as a neurological disorder so a group of organisations banded together and wrote a long, very scientific argument as to why Chronic Fatigue Syndrome should not be considered a somatoform disorder but rather a neurological disorder, and went to essentially an appeal hearing in Baltimore, Maryland on September 14th and presented their argument, their document, and what we were told is that based upon the strength of that document, and the scientific arguments, that in fact Chronic Fatigue Syndrome would be retained as a neurological disorder and not moved into a somatoform disorder. So we are very pleased with that but we certainly want to maintain that from this point going forward.

05:17 *Interviewer:* Asks question about difference between Neuro and Somo disorders... Ken explains. Talks about prejudice against people who work in the field, the difficulty in getting disability insurance payments, and doctors under investigation for treating biomedically, including Myhill, and one other whos name is not yet in the public domain and is not given here either.

10:00 Talks about his SOK presentation April 6th this year and the prejudice against researchers and patients and doctors. "The underlying thing (belief) is that if you don't have a test for it, then it doesn't exist" Goes on to talk about sectioned patients in England and forcibly removed children in the US

15.30 Music break

18:44 Interviewer: "Did the conference hold out hope for any of these situations in its attempts to change the view of CF and of new research?

Ken: I think there is - um - I think we all, both patients and researchers and healthcare providers left the conference with a much more positive attitude, and I think that because we all left knowing that it is still a puzzle and that we do not have all the answers or know all the pieces of the puzzle but that we are divising a method or methods of working with the pieces of the puzzle. For example, there are now at least four different definitions of Chronic Fatigue Syndrome, and we think we have a pretty good research definition of Chronic Fatigue Syndrome and a pretty good definition for diagnosing and treating Chronic Fatigue Syndrome.

Interviewer: Care to share any of those?

Ken: Well the research definition that seems to be used is something called the Fukuda case definition, Fukuda et al, which dates back to 1994, and that definition has been used since that date forward. It is much more restrictive a case definition than one would like to see used on patients, but it helps to define a patient population that is relatively suffering from similar symptoms and so therefore for research purposes you are apt to get results that are clearly defined

Interviewer: So it's a conservative definition

Ken: A conservative definition that may exclude some patients and therefore is not workable in a clinical situation.

In the clinical situation, you want something that is more relaxed, or a more inclusive definition, and there are actually a couple of those. There's what's called the Canadian case definition, which was developed in 2003, 2004, and that seems to be very good at identifying patients and their key symptoms, and having them diagnosed as having Chronic Fatigue Syndrome and then there is a brand new one that has been developed in 2011 that is called the International case definition, and that one is essentially too new for anyone to have any sense of how it will fare, as either a patient case definition or as a research case definition.

But what seems to have happened at this meeting is that there seems to be agreement that we will collect data or get information from each patient that will permit us to diagnose patients using several of these case definitions, (interviewer: really?) so that the information will not be lost, and so that we will then in retrospect be able to see which case definition works best, both in the clinical situation and in the research situation, and that's a much more intelligent approach than trying to squeeze all patients into one case definition, and obviously excluding some patients from treatment because they don't fit this particular case definition.

(i.e. suck it and see. This bit really worries me. jc)

One of the interesting papers that was presented at this meeting was by a clinician, I believe he's at GW, near Washington DC, was sort of a courageous thing, what he did was he took his Chronic Fatigue Syndrome patients, and he treated them for Lyme

disease, and approximately a third of them improved, their physical condition improved when treated for Lyme disease. Its not sure exactly what that means. We're not sure whether that means that approximately one third of the patients in his patient population had Lyme disease, and were just missed with the Lyme disease diagnosis, but when they were treated for Lyme disease actually improved, or whether the actual, or their particular kind of Chronic Fatigue Syndrome is susceptible to the same sort of treatment with anti-biotics that are used in the treatment of Lyme disease, so that there is at least potential overlap between Chronic Fatigue Syndrome and other illnesses, and this is something that needs to be looked at much more carefully.

24:15 Interviewer: And you spoke of multiple causes too, or multiple origins?

Ken: Yes, I do believe that there are multiple origins, and I believe that the majority of clinicians and researchers at this meeting were coming to this point of view. Because there are a number of infectious agents that have been found to be initiators of the illness cycle in patients. One of the names, former names of Chronic Fatigue Syndrome was chronic Epstein Barr Virus, and now there is work to show that patients that get sick with other viruses also develop Chronic Fatigue Syndrome. HHV6 for example, and enterovirus. If patients do not recover from these viral infections they can develop Chronic Fatigue Syndrome. So it would appear that Chronic Fatigue Syndrome is essentially the body's response, or perhaps the body's immunological response to an infection that isn't cleared from the body, which might argue that the people in whom this occurs have immune systems that are unable to clear these infections and therefore Chronic Fatigue Syndrome represents an immune system abnormality or defect because these patients lack the ability to clear these infections from their body.

Interviewer: And they have an immune system what? Inability?

Ken: Inability or defect to clear these infections from their body and so they persist.

Interviewer: Yes, I think immune abnormalities have long been found in Chronic Fatigue patients haven't they?

Ken: Immune abnormalities have been found. The problem is that there isn't one consistent finding. And perhaps the reason for that is that there are these sub-categories of Chronic Fatigue Syndrome patients and that if we define the right subcategory of Chronic Fatigue Syndrome patients then we may be able to find a clear, uniform, distinct pattern of immunological abnormalities in a subset - in this particular subset of Chronic Fatigue Syndrome patients.

Interviewer: So then the job becomes defining the subsets?

Ken: Absolutely. And researchers are beginning to turn their attention to that, and some of the questionnaires that are being developed to screen Chronic Fatigue Syndrome patients are beginning to ask questions that will assist us in being able to differentiate the subgroups and perhaps the infective agents that are precipitating Chronic Fatigue

Syndrome in these patients.

27:20 Interviewer: So this is a hypothetical, broad immune response to neurological agents of possibly many origins with a common human adaptation to it which involves fatigue and neurological abnormalities and consequences - am I correct? Is this what's hypothesized?

Ken: Well the agents are believed to be infective, and they don't necessarily have to be neurological, although some of them may be. There is another theory that's beginning to go around now, and that is that if infectious agents are not cleared from the body they can establish themselves in one or more of what's termed the body systems, for example the gastrointestinal tract or the central nervous system or in the cardiovascular system so that we are now beginning to see at least the suggestion that things like cardiovascular disease or hardening of the arteries or the deposition of plaque in the arteries is not only caused by the deposition of cholesterol, but might also be the reaction to some bacteriological agent that has been deposited in the blood vessels and therefore the plaque is an attempt to cover up or seal off those kinds of infections. And so Chronic Fatigue Syndrome in an analogous manner may be a reaction that is akin to that kind of mechanism

29:15 Interviewer: Yes, there are so many effects, and now you are saying there are so many agents

Ken: Well, the idea is to tease them out. I'm pretty exited by it because I think what we are beginning to see is a whole new area opening up to us about how infection invades the body and the consequences of it. And so that what we discover about chronic, what I would call hidden infections in the body will be applicable to a whole variety of diseases and answer a lot of questions that have been around for a long time but have never been answered before. And this will give us a tool, a mechanism of possibly providing answers to these questions.

30:00 Interviewer: What else came out of the conference that you took away?

Ken: What I took away from the conference is first of all the willingness to work with multiple questions that lead to the possibility of diagnosing patients by multiple case definitions. I think there is a renewed excitement in the involvement of the brain in Chronic Fatigue Syndrome because there is more evidence of different kinds. I think there is also a lot more work in the area of genetics and Chronic Fatigue Syndrome. People are looking ate genes being turned on, being turned off in what I call the subsets, or some subsets of Chronic Fatigue Syndrome versus "normal subjects". They are being able to find differences, or particular genes being turned on and turned off. And based upon that they are looking for proteins, or protein differences, or differences in concentrations of proteins between patients and normal controls. And so we are beginning to see what the differences are between normal controls and patients with Chronic Fatigue Syndrome. And this is all very exciting because eventually we will be able to understand the differences between normal healthy people and Chronic Fatigue

Syndrome patients by understanding the difference in the molecules that they are producing. And once we do that, we should be able to alter, or change back, or normalise the molecules that they are producing that are producing their symptoms.

32:15 Interviewer: Wow! And that sounds quite in line with current research too, it doesn't sound far afield

Ken: No, it's not far afield, and what it means is that there is new excitement, and that the field of Chronic Fatigue Syndrome is keeping up with the more advanced technologies and people are beginning to apply those technologies to the field of Chronic Fatigue Syndrome. Not only are they beginning to apply it to the field, but they are also obtaining results, significant results that will eventually lead to better treatments.