

Monday, November 21, 2011

Mt. Sinai ME/CFS conference report - Sunday November 20, 2011

by Chris Cairns, The Patient Advocate

It was with an air of anticipation that I walked up 5th Avenue early on a fine Sunday morning, heading to the ME/CFS conference at Mt. Sinai Hospital. All my hopes and anticipations were realized - and were exceeded, very much exceeded. It was a remarkable day and we have Dr. Derek Enlander and his colleagues at Mt. Sinai to thank for this.

The conference began at 11 in the morning and ran until 4:30. Dr. Enlander set the agenda and guided the series of lectures in his own respectful and low-key fashion. Like Dr. Malcolm Hooper, Dr. Enlander employs understatement, refusing to draw disproportionate attention to himself. Yet, Dr. Enlander has a manner of presentation that allows his steady, confident personality to be felt. As usual Dr. Enlander is “all there, all the time”, as has been his habit for a long time. Talk to any of his patients and you will get this same appreciation and respect. I was tremendously impressed with how he ran this conference. All speakers kept to the schedule and the conference ran like clockwork.

This was surprising to me - as the conference had only been organized in the last three weeks. From the modest beginnings of a “collaborative meeting” between Dr. David Bell and Dr. Derek Enlander, this situation quickly and seemingly naturally morphed into a full day conference, first with the addition of Dr. Kenny De Meirleir and later Dr. Eric Schadt and Dr Miriam Merad. Additional speakers were Rich van Konynenburg, an independent researcher, and Dr. Strayer from Hemispherix. Dr. David Bell was unable to attend the conference due to illness, but he is solidly on board with this effort – and we will see him at the next conference. Dr. John Chia was invited to the conference but was unable to attend. Look for him in the future.

This event followed the format of the InvestinME conference in the UK, one day filled with hard-hitting research and treatment presentations. If anything, this day was even more deeply focused - which is really saying something. I am a great admirer of Richard and Pia Simpson, and what they give us with the annual InvestinME conference in London.

In the first lecture, Dr. Eric Schadt gave an overview of his systems biology approach to research. This will be applied to ME/CFS in order to get at the underlying pathology. Dr Schadt, a geneticist, is quite astonishing in his approach and presentation. Dr. Schadt brings a great deal to the table. He is seen as the very cutting edge of figuring out complex relationships. Part of Dr.

Schadt's work will be to continue and expand the research of Jonathan Kerr. [Here](#) is an article in Esquire about Dr. Schadt.

Dr. Merad, an immunologist at Mt. Sinai, spoke of her work in innate immunity and its relations to ME/CFS. [Here](#) is a biography of Dr. Merad.

Both of these researchers are new to the ME/CFS world and are part of the research team being assembled at Mt. Sinai. Ila Singh, a virologist, has also recently joined the Mt. Sinai research team. Many of us are familiar with Dr. Singh and her work in XMRV. Dr. Singh was unable to make a presentation as she was moving from Utah. She will certainly be present at the next conference.

The Mt. Sinai research team includes a geneticist, an immunologist and a virologist, all three working closely together on this project. The amazing thing is that here are three researchers at the same research hospital, all pledged to work together in a collaborative fashion towards cracking this illness. This is unheard of in the world of ME/CFS. This indicates a seismic shift. While Dr. Schadt and Dr. Merad gave indications that they do not know much about ME/CFS, they emphasized that its complexity is not that much different from other situations on which they have worked. Their response to the patients was indeed sympathetic and the two researchers must have learned a great deal about the nature of the illness and the difficulties that afflict these patients.

During the wrap-up panel discussion, Hillary Johnson asked a few pointed questions that, as usual for her, were extremely illuminating. Hillary cuts to the quick - and a sense and weight of history attends her every word. Hillary stands like a rock for the long abused patients with this illness. She is a wonder to me. Her question was : Weren't these researchers afraid to go down this road of ME/CFS research? - a road fraught with peril and the remains of many previous researchers? The Mt. Sinai researchers seemed genuinely unfazed by this. Their answer was no, no they were not hesitant. Instead, they were eager.

Hillary also insistently sounded out the depth of their commitment (in terms of hours and staff). This is a very tough question to ask anyone, essentially asking are you for real or are you a bunch of phonies? In other words, was this a sidelight for them? Both the Mt. Sinai researchers expressed in very clear terms that this was going to be a serious effort with various researchers in their labs working steadily on the project. Obviously this is a reflection of the money committed to do this work. Dr. Schadt said he had just hired twelve new people for his lab and that some of them would be working full-time on ME/CFS. It was amazing to hear this, just amazing.

Mt. Sinai has placed a bet here - and I believe that it is a winning bet.

Dr. De Meirleir flew in from Brussels for the day and gave an excellent presentation on his compassionate use of GcMAF in ME/CFS. His preliminary data, reported elsewhere, indicated that 68 of 108 patients showed improvement in at least two of the seven major categories of ME/CFS. More data will be forthcoming soon, with larger numbers of patients.

Dr. Strayer of Hemispherix spoke about past and ongoing trials of Ampligen. Dr Enlander is running an Ampligen trial in NY, joining those in Utah, NV and NC.

Rich van Konynenburg gave a fine and compressed version of his glutathione depletion and methylation blockage concept, as applied to ME/CFS. One can see an extended version of his lecture in my previous blog post. Rich can talk in a very convincing way "until the cows come home" and he was there at the end talking to patients and professionals until the lights were turned out. What a fine addition Rich was to this conference!

Dr. Enlander himself gave the final lecture, presenting information on his treatment protocol and the various options available at present - and future considerations.

The seminar room was at capacity - about eighty people, with the overflow sitting on the floor. There was a sense of anticipation and excitement amongst the attendees. This Mt. Sinai conference presented no bullshit, no fluff -just straightforward research and treatment possibilities. One can imagine an expansion with a clinician/researcher brain-storming session the evening before, combined with a dinner. One can clearly see where this is going now.

This conference happened at the right time and involved the right people.

It was a bit surprising that Fred Friedberg, the head of the IACFSME association took a "pass" on this conference. He lives 45 minutes away and saw fit to "not show up". Others from the CAA were noticeably missing. Lipkin could have walked over, but decided not to. While they were not particularly "missed", I think at the next conference, perhaps in six months, we will save a seat for them to watch a video in an adjoining room. For the CAA itself we will reserve a place on the floor in the back. The next conference is going to have to be in a larger auditorium - and it will also be packed.

It is important to emphasize that this Mt. Sinai Center has no connection, as yet, to the CFI - directed by Ian Lipkin at Columbia. This CFI effort on the part

of the Hutchins family, involving Harvard, Princeton, Yale and Duke, holds out the possibility of further serious and deep research into this illness. We can only hope for CFI success, and that they have the inclination to cooperate with their colleagues at Mt. Sinai. The two initiatives have a great deal to share - and it is time to set aside egos.

The organizers of this Mt. Sinai conference indicated that the doors are open – that they are “open to suggestion” in terms of alliances and collaborations. It was noticeable that Dr. Maureen Hanson and Dr. Susan Levine were in the audience, both of whom I imagine would be interested in cooperating in this Mt. Sinai effort. Who wouldn't? This was a very exciting day.

The conference was videotaped and audio recorded by Peter and Nicholas Cairns. The various lectures will be put online and on DVD - and perhaps in the future some short preview interviews can be filmed of the major figures in this Mt. Sinai effort. I am a great believer in getting key pieces of information out to the larger world, and short “impact videos” are one economical and efficient way to do this. This also works well for fund-raising.

I leave to the end of this post a very important acknowledgement. This Mt. Sinai ME/CFS Center is fueled by a generous gift of Dwight Merriman. None of this would be happening without this gift. It is a matching gift, and soon we will be given instruction how we can contribute to this effort that is going to have such a long reach.

At the very end of the conference, there was a profound moment where Dr. Enlander, in response to a question, extemporaneously spoke for about two minutes on the extreme severity of this illness and its ruinous effects on patients. It is clear that this physician has a deep empathy for the subject.