

**Public Comment**  
**Joseph Landson**

Hello, and thank you for allowing me to address the CFSAC today. I am testifying on behalf of my primate friend here, Sim.I.An. Sim was lately employed in a research laboratory. He asked my help in relating his experience there, because of the overlap with the ME/CFS patient experience.

Having been placed in a three-foot-square cage, Sim was repeatedly chastised for not participating in Graded Exercise. That criticism did not sit well with him, no pun intended.

Furthermore, Sim received a negative personnel review for failing to cooperate in talk therapy sessions. This was a real head-scratcher. Obviously, Sim doesn't talk, as evidenced by my testifying on his behalf today.

Finally, Sim developed health issues as a result of his laboratory service. When he applied for disability benefits, the lab denied he had even worked there, until he produced the only pay stubs he had available. (Sim holds up bananas.) After that, they mocked and minimized his condition, and gave him a paltry settlement that barely acknowledged the degree of his disability.

ME/CFS patients will recognize some of these experiences. While Sim is disappointed, he nonetheless feels his brief career was worthwhile, if only for his extensive study of human researchers, fascinating creatures that they are.

On the one hand, they engage in highly complex language processing, talented manipulation of chemicals and tools, and intricate social interactions in pursuit of continued grant funding. On the other hand, what Sim thinks they have trouble doing, is something that seems very simple. They can have trouble changing their minds. In other words, working daily with so much exacting detail, they can have problems developing a new concept or new approach to the problem they are trying to solve. Throughout history, even when researchers do try to advance a new concept of a problem or an illness, they get treated much the same way Sim was, with disdain.

The history of ME/CFS and its previous incarnations seems to be a story of the same concepts and models getting recycled over and over. It is hysteria. It is stress. It is infectious. Now we have some evidence that it is an autoimmune disease, but the evidence doesn't quite fit existing ideas about autoimmunity. Sim realizes how important it is to have statistically significant results from large aggregate data sets, but at the end of the day, isn't it more important to ask the right questions, to frame the problem in the right way? Sim and I agree that many researchers are not yet asking the right questions about ME/CFS. While it is classified neurologically, it is mostly treated psychiatrically, while not really seeming at home in either space. What space does it belong in? Will finding or making that space make life easier for all primates, be they bipedal like us, or arboreal like Sim here?

Maybe if we get a unifying hypothesis of ME/CFS that makes sense, we can all be swinging in the same jungle, to borrow a phrase from Sim here, rather than so many different disciplines each describing the illness in its own, untranslatable way. Sim thinks the fractured research vision may be contributing to the underestimation, underfunding, and continued disdain for ME/CFS and its patients. This is just a thought from a former lab primate.

Thank you for your kind attention.