

Claire Prideaux's Written Testimony: CFSAC Meeting October 2009

Hello, my name is Claire Prideaux. Prior to becoming totally disabled with CFS I was a successful, practicing attorney. Up until I became totally disabled, my illness was handicapping despite my success, making it difficult to follow through on numerous employment and life opportunities. However, I managed to find a way to make my life work for me up and stay in the work force up until the time I could not.

HISTORY: *I apologize in advance for the length of my history with CFS, but I think why I am sharing it will become clear as I develop my concerns about the CDC definition and research priorities.*

While I was diagnosed with CFS 10 years ago, I began having CFS symptoms as a 7 or 8 year old. Prior to that, I had numerous ear infections after birth. (Indeed, I was premature, and recent medical research has shown that the amniotic fluid of women who have premature babies is higher in bacteria... sorry I do not have that reference, as I do not have the where with all to catalog research that I read.) At age 5, I began experience irritable bowel symptoms. By age 12, I could run a 50 yard dash, but could not walk or run the 300 yard walk run; I also could not sun bathe without feeling ill. As a teen, I developed numerous allergies, and often complained of difficulty breathing. My mother had detected a sensitivity to paint when I was a child, but had kept me in the dark about it, preferring to send me away whenever painting was required in our home.

As I grew older, while I had noticed that my energy, significantly flagged for quite some time after periods of exertion (sometimes for weeks or months on end), the primary mode of setting off my flu-like CFS symptoms came in the form of a chemical exposures or exposures to known allergens. It appeared that my body would become overloaded, unable to handle environmental assaults, and then the flu-like CFS symptoms would appear, along with the debilitating exhaustion. The onset would be the same whether the exposure was paint, cigarette smoke, or by way of cat, yes, the feline variety.

Although I started having symptoms at a young age, I was not totally disabled by the condition--made bed bound--until age 48. Indeed, I thought I had been managing my symptoms... backing off from exertion when necessary and strictly avoiding chemicals I was sensitive to and allergens. However, within years of total disability it appeared that my allergies and sensitivities seemed to lift somewhat--I thought I was getting better. Except for the fact that my energy was taking a nose dive and showed no signs of recovery. As it turns

out, I believe my immune system was crashing. Initially, however, I was not terribly alarmed as I had been extremely exhausted before for two years without a break--an exhaustion I was able to push myself through--and had recovered.

When I look back I see a number of things that might point to a possible origin of my illness and I will report on two. Starting with the 2nd... when I had been exhausted for two years, I allowed myself to be exposed to pesticide spray in my apartment. I reasoned that I had never had a reaction to pesticides before and so what would be the harm of it. I became very sick following this exposure, developing severe diarrhea. I ended up having an emergency hemorrhoid procedure where upon I was given Cipro. I had to stop taking the Cipro within in two days, as taking it worsened my symptoms significantly, causing a fissure in my rectum, and I ended up needing surgery to repair the fissure. While waiting months for the surgery, as doctors ruled out Chron's and cancer, my symptoms increased to include fevers and delirium.

I could have taken away from this experience that the pesticides *caused* the problem. However, by then I was well versed in what seemed to be a fact: my immune system was on a tear in response to something. In this case, the pesticide, which just happened to be the trigger... the stick that broke the camel's back so to speak. Just like all the times before except that severe diarrhea with fevers was a new way for me to have an out of control immune response. Even though my response was consistent with how some people have intestinal difficulties in response to pesticides. Personally, I believe that the way pesticides affect the gut in healthy folk, while causing no symptoms, caused my immune system to turn its attention to the bacteria in my gut, which the Cipro helped along, and I believe that the endotoxins resulting from die off--an immune assault on bacteria in the gut--is what caused my severe reaction.

By this time I had come to reject the idea that I had an "auto-immune" condition. I had rejected the idea that my immune system was somehow attacking me for no good reason. I had come to believe my immune system was trying to save my life. I still do. **I think the insistence on the part of doctors and medical researchers that there is somehow such a thing as "autoimmune" disease is what is delaying insight into the cause of illness and keeping the medical field closed to a necessary paradigm shift when it comes to chronic illness. Ditto the role of genes in chronic illness, particularly since medical research now suggests that bacteria are able to turn genes on and off.**

At the end of an eight month immune response tear, after being diagnosed with irritable bowel syndrome and finding that the recommended foods only made me sicker, **I had energy for the first time in years**. Indeed, I felt better than I had most of my adult life. Unfortunately, I thought I was probably still sensitive to paint and took steroid shots to help me manage accidental exposures so that illness would not interfere with work. I did this not fully understanding how steroids work.

A few years later, when I was sick and recovering from a virus, I had an accidental pain exposure and could not afford any more time off from work and so I had a steroid shot. Not only did it prevent the onset of CFS flu-like symptoms from the paint exposure, but my energy returned and my breathing was returned to normal. Right then, I understood just how powerful an immune modulator steroids are. I knew then that I was not only masking my reaction to paint but my own body's response to other assaults. A light bulb went off regarding the danger of that and I never again took steroids. However, I believe the damage was done by then and I was well on my way to becoming more severely ill.

As for the first thing that points to a possible origin, I had always wondered about my CFS symptoms occurring around the time I owned a feral cat for a year. Something about the way I reacted to that cat scratching me had stayed in my head. (I had cats until I became allergic to them as a teen.) It seemed an odd coincidence that my symptoms started at the same time I owned that cat when my reaction to that cat was also different to my reaction to other cats.

As it turns out, in 2005 my older brother died from an infection that ravaged his lungs following surgery to help him recover from congestive heart failure (my brother also had AIDS). I learned following his death that two girls I had grown up with also had CFS (one died a year after my brother due to cancer).

All three of us had kittens from that same feral litter, a litter that was found in a rural area near a farm. While I shared a lot with these girls, and had even been in both of their weddings, I find it awfully odd that the three of us ended up with CFS after having also had those feral cats. I had seen neither since my early 20s and so I had had no idea that they were also sick as I pondered the possible connection between my illness and that feral cat I once owned.

Additionally, all three of us were conceived by our mothers shortly after they received vaccinations to come to the U.S. as war brides (WWII, that is). I often think about the role of bacteria in vaccines, my premature birth, and my eventual illness with CFS at a young age. You know, I just did not pay

attention to the fact that my three friends often had labored breathing as well as teens. It all seemed such a coincidence then.

CONCERNS:

(1) I am terribly concerned about the so called empirical definition (Reeves, 2005) the CDC adopted for CFS research, and I have signed petitions to register my concern. The definition lacks specificity, which will allow people with all manner of psychiatric disorders to be included in research, making it even more difficult to separate the wheat from the chaff when trying to figure out the cause, and therefore a cure, for CFS.

A stricter definition might exclude some people who happen to have a major depressive bout prior to the onset of CFS, however, for research purposes (and not for the purposes of determining disability), it would be wise to lose some people from inclusion in research projects who might otherwise be there than to include people who probably have no business being included in research because their inclusion will only muddy the research.

(2) I am concerned about how little the public knows about CFS and how the Reeves definition will contribute to causing more pain and suffering on the part of CFS sufferers who are already dismissed as having an illness that is all in their heads. While doctors seem to have little idea how to help people with chronic illness, the public is fed on a daily basis the latest magic bullet garnered from research often lacking in scientific rigor and imagination, and if the research is "validated," it is often validated by more of the same. Chronically ill people are often dismissed as unwilling to get well if they reject well intentioned entreaties by people who are ignorant of the science behind the science reporting and are often abandoned as a result of their "unwillingness to get well" by the same people.

(3) Doctors, whose research shows are often 15 to 20 years behind on medical research (that is, of the sort of medical research that is not offering a magic bullet or not underwritten somehow by special interests, including the pharmaceutical companies and the supplement industry), also often recommend treatment to their patients based on poor research design. I am thinking specifically about much of the "Vitamin" D research out there (not to mention research on high cholesterol, osteoporosis, etc.), particularly since it has become generally accepted that Vitamin D is a seco-steroid and acts on the body in the way a steroid does. Somehow, I am to magically believe the conclusion that supplementing this particular steroid is necessary and good or we would not produce it naturally in our bodies. (It does not take much imagination to see the flaws in this logic, and yet much of the research having

to do with Vitamin D seems to accept this premise without question.) I submit that in our culture, we are in the middle of a manufactured Vitamin D crisis that is the result of our own lifestyle choices (e.g., diet, sun, lighting, etc.) and the supplementation of Vitamin D in our foods--choices that are making Americans sicker and sicker, and yet, we are being told to consume lots of D from nearly every source. Little do we hear of the research that says, "Maybe not," "The data is not in," and "this might actually be bad for us."

(3) Management of illness... I am sickened by the very idea that medical science is, or at least appears to be, driven by big pharma. **We seem to be all about managing the symptoms of chronic illness rather than finding cures for chronic illness.** I am afraid that symptom management is no more than immune suppression. Indeed, big pharma often does not know why the medicines it produces aids on symptom palliation.

(4) I would like the CDC to invite researchers to its upcoming workshops who have some knowledge about the role of both viruses and bacteria in development of CFS in particular and chronic illness in general, particularly those who understand how viruses and bacteria can turn genes on and off.

I recommend that Dr. Trevor Marshall be invited to speak at a workshop.

Currently, I am on a protocol developed by doctor Marshall (called "the Marshall Protocol), and I am getting better... slowly. While I do not believe Dr. Marshall understands the full complexity of what causes chronic illness, I do believe he is on a right track generally, if not the right track.

In particular, I believe that people born with a heavy load of bacteria--perhaps someone like myself with a compromised immune system born to a mother who was not only carrying her own load but recently infected by a number of vaccines--may be more likely to catch a retrovirus that would inhibit the body's ability to kill bacteria. That bacteria would have the same or similar deleterious affects on the human body as the bacteria that runs rampant in AIDS patients. Indeed, when my brother came down with AIDS, he was amazed at how his symptoms mimicked mine, and except for the fact that his illness ran rampant very quickly and two bouts in the hospital with pneumonia, he was less debilitated by his illness after becoming totally disabled than I have been with CFS since becoming totally disabled. Indeed, without the Marshall Protocol, I do not believe I would have reached the same age as my brother did when he died.

Dr. Marshall's protocol may help me kill off the kinds of bacteria that killed my brother and is killing millions more with chronic illness, AND it may not be

enough. It may take understanding the various retro viruses that infect humans, as killing the bacteria alone may not be enough. I know this much at least: immune suppression is deadly and that is at the forefront of much of what is offered today to people with chronic illness.

I thank you for this opportunity to present my comments. I hope they are in keeping with the goals of this meeting.

Claire Prideaux