

Testimony
Keith Baker

My name is Keith Baker and this is my family's 24th year with ME. My brother, mother, sister, father and myself all became ill with ME in the fall of 1986 after a sudden viral onset which had evidence of EBV, Chicken pox, shingles and later possible Lyme in my mother alone. As I testified last year I am adopted so do not feel genetics explains why my whole family has ME. Also both my children have Autism now and my oldest is epileptic.

I have witnessed the grand failure of my government to respond to this epidemic. The CDC has refused to do any real epidemiological research into ME. The outbreaks have been ignored and dismissed by the CDC as hysteria. This disease is begging for epidemiologists to research the disease. Is the CDC afraid what may be turned up and that is why this research is not done.

Why has the CDC not studied the long term risks to patients with this disease? Why has the CDC not looked to see if family members are affected and at what rate. This lack of research is inexcusable. It needs to be done now retrospectively using the patients that have been kept track of by ME physicians like doctor Bell and doctor Cheney. The CDC could do this now if it so desired.

The CDC also needs to use the Canadian Consensus Criteria for all its research. The empiracle definition is flawed and included patients that only have MDD and do not have ME. If the CDC continues to study the wrong patient cohorts and not true ME patients then all research will be a waste of the taxpayers money. The CDC must use the CCC and get it's study subjects from expert clinicians like Davis Bell, Paul Cheney and Anthony Komeroff as was done by doctor Alter in his PNAS paper.

I am totally disheartened the the Whittemore Peterson Institute has had all it's grant applications turned down by the NIH since it's findings of a retrovirus was published in Science. All I can say is it is unfair and immoral. We are always told by the NIH that ME does not get a lot of research grants because not enough meritorious institutions that know how to write grants apply to the CFS SEP panel.

Well the WPI is one of the few if only Institute created to study ME and they obviously know how to write grant applications because they recieved an NIH grant prior to finding a retrovirus in ME patients blood. So why can they not now get a grant? It's not right.

ME needs more research funding. Three dollars per patient is a Joke. We are funded like Hay fever but our disease is on the level of impact as M.S. We deserve MS type level of funding. Sec Sebelious and Dr. Collins need to do something big to improve the funding level now! People are dying or just waiting to die. They deserve a real financial commitment from their government to help save there lives.

I hope this committee can get this disease the funding it deserves so my family can get our health and lives back.

Keith Baker

Whole family sick with ME 24 years