

Testimony

Keith Baker

Dear CFSAC:

Hello my name is Keith Baker and I as well as three other members of my family have had ME/CFS for 23 years.

I was the first one in my family to become ill. It was 1987 and I was 17 years old. I was living with my mother and brother at the time in Maine.

Right before I became ill my life was awesome. I had just won several state track and field medals and was a captain on my high school's football team. I loved sports and the outdoors.

One day in 1987 my life as I knew it ended. I remember the exact moment I became ill with CFS. I was running a race and suddenly I could not put one foot in front of the other. I stopped in the middle of my race and knew something was terribly wrong with me. I felt so weak and disoriented I thought I must be dying of a stroke or some other sudden illness.

My mom took me to the doctor the next day and I was given a mono spot test which came back positive. I was told I would be well in a few weeks. I rested at home and within a week I also had the chicken pox. I thought things couldn't get any worse at this point. I was told to just rest more and I would be better soon.

Well I rested for weeks and weeks and did not improve. In this time my brother and mother (53) also became ill. My brother (12) also was told he had mono and my mom suffered from the same viral malady we had plus shingles that started to appear.

The months went by and my family stayed ill. My liver became affected and I was told I had hepatitis secondary to the Mono. I was told again to rest and Mono goes away. But alas 3 months later it had not gone away for any of us and now my sister and father were showing the same symptoms.

My sister did not live with us she was 33 but visited before and during the months before and following our initial illness. My brother and I visited my dad as my parents lived in separate locations. Whatever caused my illness had spread throughout my family in a matter of months and it was not going away.

6 months went by I was still unable to go to school. My brother was even sicker than I was and he was temporarily hospitalized. My father cried to me about how he felt like all the life had been sucked out of his body.

It was at about 6 months when I started to try to home school that I noticed my brain was not the same as it was. I could not pay attention. Math had become impossible for me and I was unable to focus on anything. At times I felt disoriented. The doctors had no idea what was wrong with me one thought might have AIDS another accused me of being on steroids because of my liver. I was sick. I knew I was sick but no one but my family would believe me.

After missing a year of school had a little improvement I was able to take some classes and finish high school. I would never be able to be an athlete and run again however. I have

stayed very ill but with the help of my now wife I was able to finish my Bachelors degree in 6 years taking some semesters off here and there. I have worked some at lesser jobs but at times I cannot work

My brother has remained to ill to go to college or work. He lives with his wife but has no means of income. His dreams as well as my own have been shattered.

Hearing this story would might lead a researcher to believe this shows anecdotal evidence that there is a genetic predisposition towards acquiring ME/CFS. The only problem with that is I am adopted. I am not genetically related to any of my other family members who got ME/CFS at the same time.

I have also met my biological family and none of them have ME/CFS. I believe and have always for this reason that this illness is caused by and infection.

I wish I could say the suffering ended with my Mom, Brother, Sister, Dad and myself. However I believe it did not. My wife and I agreed despite my illness we wanted to pursue our dream of having a family. We had 2 boys and both have been diagnosed with high functioning autism. Many of there symptoms are identical to my own. GI problems, difficulty with sleep, sensory problems, a math disorder, difficulty concentrating and the older one now has POTS. I believe there condition is connected to my own.

I put a poll on a CFS forum on the internet asking parents with CFS if there children had an autism diagnosis. There were 12 responses to the poll and 6 said yes! I keep talking to parent after parent with CFS that say there children have high functioning autism too. There has been some work at the WPI showingg XMRV in children with Autism. A poster was done by MAX Prhost of the WPI showingg this. I believe XMRV and MLV's could be a connection between the two disorders and this needs to be researched heavily!

Children are being abused and mistreated with this illness and need to be protected by our government. Recently a boy named Ryan Baldwin was removed from his loving parents in North Carolina because he had CFS. His mother was accused of Munchausen by Proxy as my mother was in 1988. It seems not much has changed for the children and families with CFS in 20 years. He was taken from his parents,not permitted to talk with them, forced to physical therapy which made him worse and the foster parents were not told about his illness. When I read this I realized that nothing has changed for children and families with CFS. The parents are blamed for the child's illness still !!!!

In England it is even worse. Children are taken away from there parents there an put in psychiatric hospitals for being physically ill with ME and forced to exercise. It's archaic!! In 2005 a young woman named Sophie Mirza was removed from her home and put into a psyche hospital where she died from her ME. An autopsy latter revealed massive infection in her spinal chord! The rest of the world looks to the US for leadership we need to stop these travesties not just in our own country but others as well.

So what do we need to help us? We need more of what the WPI is doing but on a larger scale with massive government funding which matches the number of people devastated by this illness. The amount of funding our illness receives is a joke for an illness that affects over a million people in the US and cause many of them to be too disabled to work or care for themselves or there families.

I am appalled that the WPI who may have discovered the underlying cause of our illness has still not received any more government funding since there publication in Science! They should be given immediate large scale financial support as they are the only research institute that is truly studying our illness.

We need the five centers of excellence that the CFSAC recommends every year but the assistant secretary of health and Ms Sebilios ignore year after year. These centers would serve patients in so many ways that are so needed. They could conduct much needed research, educate doctors, conduct clinical trials and serve as regional centers for treatment and support to patients.

We need a complete change of past behavior and research at the CDC. The CFS patient population does not trust the CDC and feel it works only to disprove our illness is a physical disease. From naming our illness chronic fatigue syndrome to diverting over 12 million dollars in the 90's from CFS research funds we have been abused by the institute that is supposed to protect us from disease.

Bill Reeves leadership has been an abomination. He has continued to ignore the viral cause(s) and immune problems in our illness. He has refused to collaborate with other CFS researchers. When the Science paper came out he actually came out before any studies were done and said he doubted it would be replicated. Talk about bias!!! It was to no CFS patients surprise then when the CDC could not replicate the Science Papers findings. We already knew the CDC's bias would follow into their research.

The CDC was also invited to the Bandburry conference last year where 30 CFS researchers had a meeting to collaborate on CFS research. Of course the CFS research team turned down the invitation. The NIH came why the CDC.

The CDC also needs to learn how to identify CFs patients. Calling people on the phone and asking them a short set of questions using a flawed case definition which includes other fatiguing conditions like depression is not going to help us. It will only further cloud research. The best case definition for the study of CFS is the Canadian Criteria which was developed by doctors experienced in treating our disease and experts at identifying it. The hallmark symptom of our illness is post exertional fatigue. Any definition which does not include this will not be able to separate us well from other conditions.

So please CDC you have a chance now to change your ways and stop abusing us. Hire someone to head your program now who will investigate XMRV and MLV's without bias. A person who will not waste money on over expensive flawed surveillance projects. A researcher who will not be out to link our illness with childhood abuse or other psycho babble nonsense. We need a person who believes our illness is real, understands the patients and will do the virology, immunological and neurological studies needed to solve the mysteries of our illness.

The last thing I will say is that we need clinical trials of antiviral, Antiretrovirals and immune modulators now. Patients are doing it on their own because the government refuses to. If the government cared about us they would help supervise clinical trials now instead of desperately ill patients having to experiment on their own. Would it not be safer if the government had doctors supervising these people with doctors who are experts with these types of medicine.

Also we need and deserve to have access to Ampligen. We have known for 20 years that it helps our condition. Why after all the years of study showing it helps us are we still denied this drug which can give at least some of us our lives back. It is cruel the way it has been withheld from us for so long. Please will the FDA finally approve this drug. It has been proven to be as safe as many other drugs the FDA has approved in the past.

Well that's all I can write now I am tired and my mind is cloudy. This is the best I can do.

Thank you

The Baker family