

Testimony
Lisa Baldwin

I want to thank the CFS community who came to our assistance during our custody battle with our son against the Buncombe County Dept. of Social Services in NC. The kindness of Dr. Paul Cheney who testified in court on Ryan's behalf, Dr. Bell who also came to our assistance. Pandora Marla Silverman - Ken Friedman and their wonderful group of people. The NJCFS Association. Whittemore -Peterson Institute and especially Judy Mikovitz. I want to thank Pat Fero with Wisconsin ME/CFS Association and our advocate Jerry Rice who have both remained by our family's side for many years. All of the ME/CFS advocacy organizations in the US and across the world and all the individuals who pleaded our case to the Governor of NC. Everyone else who posted online and brought awareness to the serious travesty of justice that occurred in our case. And Nelda Holder for helping us all by exposing the life of just what one child with CFS and his family must endure to get appropriate medical care.

This is a wonderful community of supportive people but we cannot do it alone without research and government assistance to enforce the disability rights so many of us are entitled to--but fail to get.

When our son was taken into custody, it was our worst nightmare. When you have an illness that I believe is not just ignored but resisted within a medical community...many things get blamed on caregivers and parents. We often do not have the financial means or physical strength to even be able to navigate a medical system or to get out of these medical traps. There is no doubt that if Ryan were well enough to travel that we would have been anywhere but in NC getting medical care. I believe that the medical board and insurance companies have such a powerful grip on this illness in North Carolina that healthcare with this illness becomes unattainable. Parents are blamed--instead of the systems that discriminate against this illness and the systems create roadblocks to effective and costly research and therapies.

Our family was well versed on what was happening and had advocates guiding our way, therefore we took extraordinary measures to protect ourselves and that it is the only reason that we were not totally destroyed. Medical care with this illness is horrendous in NC--much as Lyme Disease is. Chances are if you speak out against those that mistreat you--you may face the same fate that we faced. This is America and regardless of what illness you suffer from you should have federal protections. Sad truth is the only protections you have right now are those that you create for yourself. Our family was working with Senator Dole's office and the Department of

Justice trying to secure local medical care for our son. Because there is such a barrier regarding this illness and obtaining healthcare in NC--you can equate it to sort of having the plague and asking for a doctor to come to your aid. Once medical care became unattainable for our son, we audio taped the medical establishment's resistance in providing our medically disabled son with medical care. Please protect yourselves and remember it is a much larger picture than just you or a family member and your doctor. It is a system--a business and this illness is not profitable--but costly.

Because the evidence we possess is so discriminatory, we are unsure if we will ever fully expose it. As a social worker myself, it breaks my heart to see families suffer as they do with this illness and yet they are so very challenged by a medical system--as we were. We believe Munchausen's Syndrome By Proxy in our case was a tactic to get us to be quit regarding Chronic Fatigue Syndrome and it is a tactic that is used often.

I never believed that I would hold evidence to show tactics that led up to the MSBP allegations and played out on tape. I have a new appreciation for the multiple parents across the nation that face these serious and often made up charges. Please protect yourselves. I hope that we are the last family that has to ever go to these lengths to prove our innocence and I will fight every day for ME/CFS patients until the research comes out in defense of this illness. My plea to this committee is to please continue to educate and set systems in place to prevent what happened to Ryan from happening to another family. We need attorneys to take our cases and stand behind us. To imprison people who so blatantly falsely imprison children sick with CFS. Ryan was falsely imprisoned and then forced through Graded Exercise Therapy (GET) and Cognitive Behavioral Therapy(CBT) . He wrapped it up for the newspaper by stating that "I was given physical and psychological treatments designed to either exercise my disabilities away or to convince me that they did not exist in the first place." ...My question is how exactly do you think yourself well with CFS, and is it harder with a retrovirus?

Ryan was dumped back home and we were told we could now have access to his brand new \$23,000.00 power wheelchair and lift. That alone should anger this community and I ask that his committee channel that anger into effective programs to stop future abuse on children.

In addition, I ask that this committee read *Inadequate NIH Funding for CFS* by Pat Fero. I support the recommendation that the CFSAC began investigations to focus on how researchers went from a funding rate of 24% to 6% for grants where "CFS is the primary focus."

Thanks for your time.

Sincerely,
Lisa Baldwin, BSW