

Dear CFSAC:

My name is Jerry Rice and I have been an advocate for 23 years in western NC . I advocate in a 7 county region –including Buncombe County NC. I became an advocate for Ryan Baldwin and his family in 2004. Ryan who was diagnosed with CFS in 2004 was taken by the department of social services in 2009 and returned to his family only after a horrendous 10 months in DSS custody.

We live in an area where our local hospital Memorial Mission has been named one of the top one hundred hospitals in the nation for heart and endocrinology care. The local hospital system has just bought out Asheville Cardiology -the biggest independent group medical practice in Buncombe County. Currently Mission Hospital is buying up individual medical practices from one doctor to many doctors at a very high rate of speed and with very intense negotiations.

We have one very large children's medical center located here with the very same hospital running it – the name of the children's center is Reuter's Children's Center. The purpose of saying all of this is that I have been advocating for children with multiple disabilities in school systems for many years and one of the primary problems is the large number children being classified under the emotionally disturbed category and the other health impaired category. One of the biggest trends that I have seen in Buncombe County over these years has been the high number of autistic children being identified either on the low end or the high end of the spectrum. In working with the children and their families, I find that their biological parents are suffering from a lot of the same symptoms. Autism is especially interesting to me because the TEACCH center located in Chapel Hill NC has a satellite office here in Asheville NC and has been here for close to 20 years or better. At one point in time there were so many children being identified with autism, the local school director of the largest county asked the director of special services to slow down on identifying so many children. The identification of autistic children is capped at 12.5 % in NC .

AS far as diagnosis goes , Ryan Baldwin is the only child that I have met that has a confirmed diagnosis of Chronic fatigue syndrome . I have never even heard of another child in all of western NC or the state of NC with a chronic fatigue syndrome diagnosis.

When Ryan is in severe relapse there appears to be severe brain involvement. At his worst with an acute infection, he is unable to tell time on an analog clock and his writing becomes dyslexic. His memory also becomes severely impaired.

Ryan Baldwin also had a long list of medically recommended school accommodations that were never enforced. Since I have never heard of another child in all of western NC or the state of NC with a chronic fatigue syndrome diagnosis, is it possible that CFS is prevalent here in our county but called by another name?

I also have not ever assisted one child with Lyme Disease. One family I assist has two children diagnosed with Ehlers Danlos syndrome and another related parent and child from that same family awaiting diagnosis. I have never met anyone with a confirmed diagnosis of mitochondrial disease although statistics state that one child is born about every 30 minutes with that illness.

On the other hand, I have met many adults with severe fatigue and a confirmed diagnosis of Fibromyalgia, rheumatoid , arthritis, lupus, and what appears to be immune system problems.

In the last 10 years this town has added what appears to be a drugstore on every corner-either built or being built. Our local Buncombe County commissioners have adopted a resolution for reduced drug costs. They offer a free prescription drug saving plan up to 65 % on brand name and generics saving up to 20 to 40 % depending on the medication. The card is good for an entire family. You can learn more at buncombecounty.org/rxcard.

Ryan Baldwin is the only child I know of who has been diagnosed with CFS –and shouldn't the fact that he is the only one child in Buncombe County with CFS - - who was taken into DSS custody-shouldn't that fact alone raise eyebrows? He also is XMRV positive.

"In addition, I ask that the CFSAC read INADEQUATE NIH FUNDING FOR CFS, a paper submitted by PAT FERRO. I support the recommendation that the CFSAC began investigations to focus on how researchers went from a funding rate of 24% (GAO report 2000) for grants where "CFS is the primary focus" to the current 5- 6% funding rate for grants where "CFS is the primary focus."