

**Public Comment**  
**Kyle York**

In the fall of 2001, Kyle came home from school one day after running track; he said he had a headache. That was the first symptom that began many years of illness, which is still current. In a short amount of time, he was not himself. He started getting pain in his body and was showing signs of lethargy, unable to concentrate on large or small tasks. Playing with friends, talking on the phone and going to karate class were activities he could not continue.

Kyle saw his primary doctor often. After many blood tests and referrals to neurologists, rheumatologists and therapists; she could not help Kyle. She was not sure of the exact problem because many tests would return within normal limits. This is what we were told from the other doctors as well. CFS was his diagnoses in February 2002.

In April of 2002, he could not attend school anymore. The same lighting and noises that he was accustomed to became unbearable, besides the fatigue and pain he experienced. Kyle remained being tutored throughout the remaining years of his high school education. The school board and teachers did not understand the illness nor did they care to understand or pull for him to succeed. CFS can be very deceiving, sometimes a person with this illness may look normal to people that don't know them well. We feel the biggest thing is bringing awareness to everyone so that the ill are not forgotten or judged as lazy.

Unfortunately, this illness won't let the affected people speak for themselves because it takes all their strength to do the simplest tasks, such as opening up a Gatorade bottle needed for fluid, feeding themselves and doctor appointments. Shopping is a nightmare, and the joy of driving was stripped from him. The simple act of sitting through dinner or watching a movie is very difficult. CFS, fibromyalgia, coxsackie virus, weight loss and short term memory loss have changed his life and many more people are also struggling to live.

Support groups and nonprofit groups need funding. Research funding is needed. Since Kyle was diagnosed with CFS, his life has gone bad to worse. It will be 12 years this fall of Kyle's everyday suffering of weakness and pain. The hope of leading an independent life to Kyle feels lost. Without the support of people who are living this, there would be no hope at all. We would like to thank Marly Silverman from PANDORA, who visited our home today to give hope to Kyle. It was great to see him smile again. Without funding for research and support groups to make people aware of this illness, they would not have hope. These patients deserve more funding for research, educating people about this disease seems to be left up to the ones who are ill, fighting just to stand up in the morning to or enjoy the little time they can or just to survive the day.

Why are we ok with people not fighting more? They need a voice, and we need help to give them a voice. There is too much suffering in this community. It's time for everyone to pay attention. My son is 24 and trapped in this old crippled body, blinded by fog that sits in his mind most days. Kyle York deserves attention as well as way too many who are suffering. Kyle is not lazy; he didn't do this to himself; he never got the opportunity to work or earn money. We do everything we can to afford as much as we can and will never stop. We are currently struggling

to find an affordable primary care doctor that will deal with his disease. He is on Medicaid and should not be denied medical help because of this. There has been a lot of discoveries in the 12 years he has been ill, and I have faith in science, and with more funding, there is a whole lot more to come.

Our family would like to acknowledge all the strong individuals who keep their head up high with their struggles every day. Our son is an amazing young man who never asks for pity or feels bad for himself. He is the most giving and honorable young man; he gives our whole family strength. How amazing is that? Please help us understand CFS so we can help those who are suffering and not able to live life to the fullest. Let's not let this disease out do us. Let's fight it head on and do everything we can to help those in need, together we are stronger.

Robin and Joseph York