Public Comment

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I am writing today, as the mother of two children with CFS, in the hopes of raising awareness that CFS is an illness that impacts children and adolescents as well as adults. There has been a dearth of research and development of safe and effective treatments for CFS in Children and adolescents.

When children begin to display the symptoms of CFS it often takes years to get an accurate diagnosis; years in which the child's development is proceeding at a mind boggling rate. Many of the messages that health care professionals give youth are inaccurate and damaging at these impressionable ages; dismissed as growing pains, depression, somatization, secondary gains…parents told to worry less, attend less to their child's report of multiple symptoms. Dr. Katherine Rowe (Royal Children's Hospital, Melbourne AU) studied adolescents and found that they frequently reported the delays in diagnosis, the tendency for doctors to see the illness as "all in your mind" and lack of belief are significant life stressors. Parents are advised to push for school attendance. This advice leads to further strain on the already weak immune functioning and leads to disease progression. When an illness takes your life away as CFS often can; it not only leads to suffering and loss it also complicates the developmental trajectory of that young person. Their life path is altered. They miss out on many of the social, educational and recreational experiences that are so important in the development of an autonomous sense of self: making it all the more difficult to transition to adulthood. Dr. Peter Rowe's (Johns Hopkins, Baltimore, MD) study of the quality of life of adolescents with CFS found that Quality of Life ratings for adolescents with CFS were poorer than those with cystic fibrosis, epilepsy, diabetes, sickle cell disease and renal transplant. Adolescent futures are uncertain and with so little known about effective treatments it is impossible to predict how their disease will progress.

Having two daughters with CFS has placed enormous stress on our family. Our medical bills include emergency room visits, hospitalizations, EEGs, MRIs, EKGs, multiple blood draws, CPET and spinal tap due to the ever changing symptoms which vary in severity and duration. I have reduced my work schedule, taken leaves of absence and passed up promotions to care for my ill daughters. It took us 5 years despite our best efforts for our eldest daughter to be properly diagnosed. By that time she had graduated from High School having been homeschooled due to illness and a failure to procure adequate accommodations at the local high school since a diagnosis is needed to obtain a 504 or IEP. We were compelled to file a costly complaint against our local school district in order to obtain special education services that were responsive to the severity of our younger daughter's illness. These issues pale in comparison to the pain and multiple losses associated with parenting adolescents with CFS. My bright, creative, compassionate children are only rarely able to engage in activities outside the home. Pain is their constant companion. Heart rate and blood pressure anomalies make standing for any length of time difficult. Tasks of daily living such as showering and brushing their teeth are exhausting. There are days when my youngest daughter cannot carry on a conversation due to difficulties processing what is said to her and the challenge of formulating verbal responses are taxing because of her severe brain fog (despite recent psychoeducational testing placing her abilities in the 99th percentile in verbal expression.) My daughters continue to strive towards their goals, and struggle to live their lives as fully as CFS allows. Our story is not unique, there are many thousands of children and adolescents with CFS that are struggling to hold onto as much of their lives as possible.

CFS remains a poorly understood illness with no cure. Potentially effective treatments remain in the experimental phase of development. Efficient management of “energy envelope’ and symptom management are the primary targets of most interventions. Many people (including many health care professionals and educators) remain unconvinced of the veracity of this illness with its ever changing constellation of symptoms and suspected psychological connections. Certainly chronic illness is often comorbid with depression. With other illnesses, such as MS, if you are depressed it is not seen as verification that the symptoms of MS are psychosomatic. However if you have chronic fatigue the symptoms are attributed to psychological factors. This is backwards. Chronic fatigue is an illness that takes your life away and this can lead to depression; what is amazing is that it often does not. CFS is a real illness that disrupts immune systems, autonomic nervous system function, cognitive output and cellular energy production. There appear to be both genetic and infectious elements involved.

It is imperative that research into the causes and treatment of this illness be funded commensurate to the funding received by illnesses such as MS. CFS needs to be fully recognized by the entire medical community as the seriously debilitating disease that it is. The fact that there are millions who suffer, many of them children and adolescents, from this disease that has been so ignored is appalling. We can’t change the severe underfunding in the past but surely there is more than sufficient evidence that the suffering caused by CFS is worthy of a significant increase in funding for research and development of treatments. I wish to make a further plea that some of this funding be directed toward research that is specific to children and adolescents as they are not simply miniature adults. These children and teens that suffer from CFS deserve a more certain future.

Respectfully submitted,
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