

Public Comment
Peter Madden

My name is Peter Madden. I am a 25-year-old journalist from New York City and recent graduate of the Columbia Journalism School. Every student there must produce a master's thesis to graduate; 4,000 words on any subject worthy of such lengthy treatment. I chose to write about ME/CFS.

My father was diagnosed with chronic fatigue syndrome when I was young. He left work on disability and later retired. I remember him, so angry with those who thought him a liar, so desperate for relief from a revolving door of doctors and specialists and so-called healers, so addled by the pain he perceived and the painkillers he was prescribed that I barely recognized him by the time he left our family.

My master's thesis began as an investigation of my father's illness. I started with very basic questions. What is it? How do you get it? Can it be cured? I suppose I should be disappointed that I'm still searching for answers to these questions (along with ME/CFS patients, advocates, and researchers, unfortunately), but that quest brought me to Laura Hillenbrand, who supports the CFIDS Association, who introduced me to the Lopez-Majano family.

During my investigation, I read about a woman who overcame crippling fatigue to publish two epic histories of courageous victory that parallel her own; I spoke to advocates and researchers (like Dr. Peter Rowe, Drs. Alan and Kathleen Light, and Staci Stevens) who overcame the stigma of an invisible illness to support a patient community desperate for vindication; I met the Lopez-Majano family (made up of Denise, Alexander, and Matthew) who overcame the loss of the happy trappings of a normal life just to love one another.

In a way, what I found, in the face of so much doubt and disappointment and anguish, was a story of triumph, one that repeats itself every time Hillenbrand pens a sentence or researchers make a breakthrough or Denise helps Matthew down the stairs. With all the new questions I've discovered about his illness, I know perhaps less about my father than when I started. But I found the Lopez-Majano story, one of a struggle shared by millions of Americans—and thousands of children—that needs to be shared. I should have been looking for them all along.

Matthew's descriptions of the detachment and guilt resulting from what he perceives as his inability to make a contribution to society capture perhaps the most heartbreaking aspect of this condition, the sidelining of the young, the eager and the talented. I'll steal a quote from my favorite movie, *A Bronx Tale*: "The saddest thing in life is wasted talent."

Educational accommodation for pediatric ME/CFS patients is crucial, not only because it is a step toward acceptance, but more importantly because it carves out an avenue for contribution. That's the only way, short of a cure, to alleviate those feelings of detachment and guilt, to find a way for those who have been left behind by the pace of our world to join in its improvement.

Otherwise, we risk dooming thousands of young people to my father's life of missed opportunity and bitterness. I always resented him for wasting the talents that I admired and aspired to, but

now I'm not sure that he was given much of a choice.

Appropriate educational accommodation will vary from patient to patient depending on the degree of impairment and physical function. The educational system must recognize and support students through the wax and wane of symptoms of this chronic illness and work with students and families to ensure that the students' education is achieved at their intellectual level. Cognitive impairment typically does not equate to a drop in IQ, so students must be supported in their quest for knowledge. We must help them remain part of the world despite the limitations imposed by ME/CFS.

If you wish to obtain a copy of my master's thesis (and learn more about the Lopez-Majano family), please contact me at peter.a.madden@gmail.com.

Thank you for your time and attention.

Sincerely,
Pete