

Testimony
CFSAC, U.S. Department of Health and Human Services
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Indiana



Thank you for this opportunity to provide testimony. I include my photo in hopes that I will be recognized as a person and not merely a statistic that you discuss.

My illness began at the age of 14 with mononucleosis (glandular fever), from which I have never recovered. Before becoming ill, I was a very active student and did well in school. I was involved in marching band and was a drummer in a band outside of school. I was on the tennis team and also enjoyed skateboarding in my spare time. I had many friends and had a very positive outlook on life. Since the onset of illness, I became progressively worse while trying to keep up with normal life activities, and eventually had to drop out of school.

One of the greatest disappointments was when I realized I could no longer participate in marching band because it was the thing I enjoyed most of all. I'm sure you can imagine how difficult it has been at my age to miss so much of life.

I am currently 20 years old, spend most of my time in my room, and must carefully manage my mental and physical activity. I am only able to leave my home occasionally and I cannot drive myself. I rarely get to see my friends. I have hopes and dreams like every young person, and am counting on you who have good health and hold positions of influence to promote policies and actions to help people like me get our lives back.

I am certain you have heard this before, but I will offer again how much additional suffering occurs due to a lack of information or misinformation about this illness. Trying to find a doctor who has understanding of how to treat ME/CFS is difficult to say the least. My experience has been one in which the usual blood tests are performed and nothing of note is found. I have been presented with the idea there may be psychological elements involved and offered anti-depressants on multiple occasions. I also have had various exercise programs suggested. I have a psychologist who assures me I am not suffering from depression, and I have followed the exercise regimens to the best of my ability with symptoms always worsening. I have excellent nutrition and a positive mind-set, but I am past trying to get better by pushing myself to greater and greater activity or by changing my "illness beliefs". Been there, done that. I put forth all the effort I have into things that promote good health, but I need the help and guidance of the medical community. Make no mistake, I am not giving up but as much as I have tried, I don't think I can beat this illness by myself. Can you imagine finding out you have cancer and not having a doctor to turn to?

I ask you to provide the following:
(whole-heartedly and with passion. preferably)

- Better information to the public and education for the medical community.
- Fast-track clinical studies for treatments and medications.
- Funding that is in alignment with other chronic illnesses.



With band friends before I became ill.