

## Testimony

Melanie Pruitt

Hello,

My name is Melanie. This December at Christmas time marks 10 years since I caught the virus that led to this long road of illness with ME/CFS. My youngest child is 18, which means he's lived more years with a very sick mother, than not.

I have been a committed attendee to the CFSAC meetings - getting up very early to listen and watch online from my couch here in the Pacific Northwest.

First, I want to sincerely thank each and every one of you for your continued interest and the heart you show for patients like me.

I have never added my voice to the public testimony before, but this time, I'd like to share with you two things that have become incredibly important to me.

First, living here in the Pacific Northwest means that I am very far away from any of the great specialists that care for ME/CFS patients. Several years into my illness, I had to fly across the country to even get an official diagnosis.

I have heard it said, that if my doctor isn't familiar with ME/CFS, or doesn't acknowledge it's existence, that I should find another doctor. But that is not as easy as it sounds.

No doctor's office will tell me if they deal with ME/CFS patients due to confidentiality rules. To meet the doctor, I must go for an initial appointment, which I rarely have the energy for. I went for one such

appointment, and the Primary Care Physician I had at the time immediately dropped me because I was “seeing” another PCP.

It takes a long time to get to know a new doctor and develop a relationship of trust. It takes a long time for her to get to know me and trust me. Changing doctors over and over gives me a bad reputation.

I have also found that, though a doctor may sound like they are willing to care for a patient with ME/CFS, they may not actually know anything about it. I have yet to come across a PCP who is willing to invest their time into fully understanding my illness.

My first, urgent request is that you continue to address and pursue ways to educate Primary Care Physicians on ME/CFS.

I try hard to bring straightforward, reliable information with me to my appointments without overwhelming my doctor, but it would be so much better if there was one reliable place that I could direct my doctor to.

PCP's today need information to be efficient. We need an authoritative resource for our PCP's. Maybe it could be organized by symptom so it was quick and efficient. Then my PCP wouldn't have to learn everything about ME/CFS all at once, but could help me, and learn piece by piece. Even though there are no ME/CFS specialists in my area, I have come across caring PCP's that would make use of such a resource.

You all understand the need for efficiency. You understand the need for information to be from a reliable source. So I plead with you to remember this everyday need of patients like me.

Secondly, I have had the great privilege of traveling to be evaluated and treated by one of our top ME/CFS specialists. I am a middle class American, one that is lucky to have good health insurance coverage.

And yet, even with this high profile insurance company, I have spent 8 months working with one representative, to get my visit with this specialist covered. I was told by my company that they would cover this visit, and told by the provider that appropriate codes would be provided so I could get reimbursed. And yet, it has taken 8 months for these codes to be coordinated and I am still waiting on codes and items to be processed.

It seems it all comes down to billing codes! And ME/CFS issues are not included in regular coding. I am not trained in medical billing codes, but clearly, if this very large insurance company is struggling to coordinate codes with this wonderful provider, something is wrong.

I urge you to continue to address the issue of insurance, coding, and ME/CFS.

Aside from the expense and difficulty traveling with ME/CFS, I find now, that I can no longer afford medical treatment from a specialist for my ME/CFS even with one of the best insurance policies around. And you can hardly imagine what hopeless feeling that is.

Thank you for hearing my concerns today. Thank you for caring.