

## **Public Comment**

### **Lori Chapo-Kroger**

As the president of PANDORA Org, we note that the CFSAC has a presentation planned on how to attract clinicians to caring for ME/CFS patients and that the centers of excellence recommendation has been made at least 4 times.

I would like to share with you PANDORA Org's experiences in trying to reach these goals as a nonprofit organization.

In Alabama, myself and another PANDORA Org representative met with hospital administrators and doctors who expressed interest in increasing knowledgeable health care for fibromyalgia, ME/CFS and chronic Lyme disease patients. They expressed the following obstacles:

1. A misconception exists that most patients are on Medicaid
2. Evaluation and care for these patients is time consuming making a clinic for these diseases not financially viable
3. The field lacks credibility among medical professionals

These administrators said they thought a large number of these patients use Medicaid, which would make caring for these patients unattractive because Medicaid does not pay as high as Medicare or private insurance for the same services. PANDORA ORG'S survey showed that private insurance was the primary way these patients pay for clinical services. This misconception could become an obstacle in convincing administrators or clinicians to provide health care for these patients.

The primary obstacle given is that these patients take a long time in the clinical evaluation, and patients come back often. We were told that some doctors who treat ME/CFS remain in the closet because they don't want their clinic to go bankrupt.

Having a few of these patients will have minimal impact on the finances of the clinic, but as word gets out that a clinician is literate in these diseases more and more patients flock to that clinic. One rheumatologist told us that when he started caring for fibromyalgia patients at a large clinic, the clinic's administrator explained to him that he was not even bringing in enough to pay for his malpractice insurance. He went to the local VA hospital. So, that large clinic no longer has a rheumatologist who is willing to treat these patients.

The fact is that health care in the United States is an industry and clinics are businesses, unless it is part of an academic institution. The current insurance and Medicare payment system makes a clinical care center for these chronic multi-system patients a losing business venture, unless it is a concierge clinic which would serve only the more affluent.

We ask you to make the recommendation that the DHHS form a task force with current ME/CFS, fibromyalgia and chronic Lyme experts, patient representatives and even outside professionals to come up with a unique business plan for a financially viable private center for neuro-endocrine-immune diseases or other chronic illnesses. Until we solve this problem, the main street clinician will continue to avoid these patients. It's not that they don't care; it's simply a necessary business decision.

Another concern we heard is that the ME/CFS research and clinician field is tainted by unvalidated claims of discovery and unproven claims of treatment results. So, any clinician who gets involved in ME/CFS or post-treatment Lyme patients will lose the respect of their peers. Frankly, due to many things that have happened in the past, our illness has a credibility problem. I'm not talking about whether it is real. I'm talking about the perception that anyone establishing a practice for these patients and offering non-FDA-approved treatments is considered a quack and unscientific.

Contributing to the lack of credibility is that no specialty embraces these neuro-endocrine-immune diseases. We're the proverbial hot-potato. We belong to all the specialties, yet none of them want us.

Establishing a medical specialty for these chronic multi-system illnesses and having it taught in medical schools will increase the field's credibility, making it more attractive. Where and how do we make this happen? We don't know. But I bet some of you do.

In the meantime, PANDORA Org will continue to follow whatever opportunities open up for physician education to increase access to knowledgeable health care and any interest for creating a center for these chronic multi-system illnesses.

Anyone who wants to discuss this with me can email me at [info@pandoraorg.net](mailto:info@pandoraorg.net).