

Public Comment

Marcie Myers

Dear Committee Members,

I regret that I missed my 11am called today to testify via phone to the CFSAC.

I am so very crashed. I hope that someone will see the letter below that I'd send to Jennie Montgomery, newscaster for an Augusta, GA local channel WRDW. She had called the Medical College of Georgia (recently renamed Georgia Regents University, GRU) in regards to my concerns as outlined below and was told only that "Dr. Hobbs is aware".

Dr. Joseph Hobbs is the head of the Department of Family Medicine at MCG/GRU. Dr. Pelletier is my current primary practice MD there though I've only seen him once. My next appointment is this Friday.

I would appreciate it if in lieu of my phone call that someone would just read this aloud and discuss its implications. The specific names of the physicians need not be included as I'm not trying to make any type of personal attack but rather to just..... get their attention.

Sometime mid-April I called and left a recorded message for Drs. Hobbs and Pelletier on the "MD line" stating my dissatisfaction with the lack of knowledge base regarding how to properly diagnose, manage and support patients with CFS/ME in the Family Medicine Clinic. I included the fact that Dr. Hobbs had never called me back in spite of my four attempts to contact him by leaving very clear messages with his administrative assistants and double-checking that he received my messages.

The first MD I saw at the Family Medicine Clinic, Dr. LeClair, had not even glanced at the Primer for Primary Practitioners that I'd brought him weeks prior to my initial appointment. His response? To impatiently refer me to Endocrinology, Rheumatology, Immunology, Infectious Diseases (who I never heard from...??) only to be informed by each of these specialties that CFS/ME was NOT within the "scope of their practice" and I was essentially dismissed from further appointments. Dr. LeClair admitted he knew nothing about ME/CFS and did not have ANY patients with this diagnosis. This is a teaching hospital. How could the Family Med group be so uninformed?

Admittedly, my recorded message essentially read them the riot act though I was neither rude nor crude. Did I hear from Dr. Hobbs? Of course not. But on April 26 I did receive a call from

Tammy Banks, Quality Service Coordinator, 706-721-6222, inquiring as to what my issues were which I laid out to her in a succinct manner and was assured by her that I would hear back shortly. I never heard back from her at all.

Yesterday, I went to some effort to locate her and she stated to me that she would call me first thing Tues a.m. So, at 2:30pm on Tuesday I called and was told by her that she'd said she would call me "sometime today". Now it is Wednesday late afternoon and I am still awaiting her call. Consequently, to sum it all up, I have not heard anything officially from GRU.....except that Dr. Hobbs was planning to phone me this Friday at 3pm. I advised Ms. Banks that I just happened to have an appointment with my Family Medicine MD on Friday at 2pm so I would be easily able to speak to Dr. Hobbs in person. There was no response to that statement.

So, since the GRU system has left me waiting and breaking the commitment to return my calls, I'm left with..... I hadn't written my 5 minute testimony yet because I'd hoped to hear something on a positive note that I could include. Guess I'll just go with the story as is which actually makes my point:

1. CFS/ME needs to be part of the student's curriculum
2. Family Medicine and Internal Medicine MD's need to be trained about CFS/ME so that a patient could hope for a proper diagnosis and not merely be dismissed.
3. There should be a specialty designated that will assume CFS/ME under their scope of practice.
4. Wishful thinking, but I would hope that GRU would join in some of the research efforts underway.
5. The public needs to be aware that ME/CFS is a REAL disorder causing severe debilitation in most cases that cause the patient to become housebound and/or bedbound. They are NOT lazy and most could use any kind of help you could offer as they are often unable to drive, shop, cook, complete paperwork, etc. Most had careers that were important to them with many responsibilities. They would never choose to be humiliated and helpless as becomes the case.