

Testimony

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Dear Ms. Jones,

Below is my (anonymous) testimony for the Fall CFSAC meeting. Thank you very much.

I am outraged that for over 25 years (the same amount of time that I myself have struggled with this disease), hardly any serious help has been available for CFIDS—sadly in part due to the obstructionist and neglectful efforts of our own CDC and NIH (which seemingly still continue—the CDC has even recently published studies saying CFIDS is an inability to handle stress, due to childhood abuse or an emotional imbalance). This is why we patients have had very, very frustrating experiences with medical professionals, who were as stumped as us patients, in the absence of meaningful guidance from scientific research. Funding is sorely needed for CFIDS research, clinical trials, and Centers of Excellence. Such research should utilize appropriate patient groups (i.e., not skewing the results by including individuals who clearly do not suffer from this disease, as has sadly been the case with even some recent studies). The recent work on XMRV and related retroviruses has now gotten us close to the point where AIDS research was in the early 80s—we have a tremendous amount of catching up to do. It has also been noted that the silent suffering of CFIDS can be great—and in some cases has been compared to end-stage AIDS. So many lives have been damaged due to years of neglect and invalidation (in part due to erroneous “psychologizing” of symptoms by health-care providers—and even some researchers funded by our government).

In closing, I strongly urge you to do the following:

- fund fast-track clinical trials for treatments and medications
- fund Centers of Excellence just for this illness (starting with the WPI, who uncovered the link between XMRV and CFIDS)

How much longer shall we remain invisible? The time has finally come for focused, effective, decisive action!

Anonymous