

## **Testimony**

### **Kathryn Stephens**

My name is Kathryn Stephens. Thank you for this five minutes.

You'll notice Young People with ME here today. I brought my 23 year old granddaughter with me. Just as I was (unknowingly) coming down with ME, I took care of her for the first five weeks of her life. Infectious? Transmissible? I'd say yes. Her illness began at age nine with severe GI issues, then "mono" at age 14 which became "chronic" by 15. She missed the last 2 years of high school, confined to a darkened bedroom with very little care and no treatment. She has now lived with me for two years, still mostly confined to her dark room, unable to care for herself without my help.

My partner of 27 years got ME seven years after I did. Infectious? Transmissible? I'd say yes.

I want ACTION on adopting the Canadian definition (CCC). I want ACTION for patients to be allowed appropriate testing for viral and infectious co-factors/causes of their illness. I want Internal Medicine and Infectious Disease doctors trained with the CCC. The CDC denies this for their patients under their "CFS" construct. I want all patients given the diagnosis of CFS be re-evaluated according to the CCC and put into the appropriate ME or CDC-defined "CFS" categories. We have a basic human right to an appropriate name for our illness

EBV, HHVs 4-8, CMV, XMRV and various Mycoplasmas have been implicated: I want all the viral panels and immune system factors investigated, and my family wants these now. To this end, I suggest CFS patients be seen in Infectious Disease clinics immediately, with the same benefits of Medicare and Medicaid covered expenses, as are the HIV/AIDS patients. I want compassionate care meds available to them, as are for HIV/AIDS patients. To do less violates our human rights and is criminal patient neglect.

To do this, I want the NIH to designate \$200M dollars, with \$150M going to the existing clinics performing these services already: the WPI, the University of Miami, Stanford's Dr. Jose Montoya, and others needing funding to open. The other \$50M should be used to pay for the re-evaluation of all diagnosed CFS patients at Infectious Disease clinics nationwide (who could also be enrolled in studies to publish the results of all this testing).

I would like the CDC's CFS program shut down; mental illness does not belong in the Infectious Diseases and Pathogens department. The NIH should take charge of ME at once.

I want urgent new training tools for American physicians, including VA physicians, using the CCC, in order to get patients diagnosed correctly in the future.

CFSAC Committee members, I thank you for your service; however, have you gone to YOUR Congressional Reps about the epidemic (nay, pandemic) of ME? Have you, as a group, ever requested an urgent meeting with any of the current or past Secretaries at DHHS, when the Recommendations have not been addressed? I daresay, if you or a family member gets this illness, you would not be as polite as we have been, as polite as you are still asking us to be. Be prepared for less of that.

Thank you.