

CFSAC Meeting of Oct 13-14, 2010

Testimony of Rivka Solomon

Dear Health and Human Services Secretary Kathleen Sebelius,

I have spend way too much of the past 20 years bedridden and homebound with Chronic Fatigue syndrome, an illness with a belittling name for a disability so severe.

According to the Centers for Disease Control there are 1 to 4 million Americas like me, all sick with ME/CFS.

Every year of the past 20 yrs, I hope and hope that my government will do what a government is supposed to do, and help its people -- help me. But every year I am deeply disappointed.

The National Institutes of Health, the NIH, invests \$31 billion dollars annually in medical research for the American people. But of that \$31 billion, in 2009 CFS research got \$5 million -- about the same as what the NIH dedicates to Hay Fever, and about a 1/3rd of what is dedicated to Psoriasis.

Now, with a newly discovered retrovirus called XMRV that is linked to -- and perhaps the cause of -- CFS, we have an even greater reason to stop ignoring the 1 to 4 million Americans who are so sick, so desperate and so in need of help.

Director Sebelius, please dedicate more money to researching CFS and the retrovirus XMRV. Dedicate more money to clinical trials so we can find treatments. And protect the Americans who have yet to get XMRV from blood transfusions, because this retrovirus is surely already contaminating the nation's blood supply.

Please help us.