

Testimony

Kathleen Fatooh

To Wanda Jones, Executive Secretary of the CSFAC, Kathleen Sibelius, Francis Collins, Thomas Frieden and Elizabeth Unger:

I am very ill and you are very busy so I won't take up much of your time with my contribution to the public testimony for the upcoming CFSAC meeting.

Another reason for keeping this brief is that today is my son's 17th birthday. I want to devote what energy I can to making this as pleasant a day for him as possible. This is the 4th birthday he has been ill.

Imagine spending your 14th, 15th, 16th and 17th birthdays---and all the days between---lying in bed: your entire span of high school years lost to constant pain.

There's so little I can do to provide comfort as I also am ill, unable to work and provide the comforts that a healthy parent can bring to a sick child, from pleasant distractions to decent medical care. In any case, there has been no decent medical care, no appropriate proven treatment, for people with our illness. But now at last promising treatment is at hand.

There is no time for us to wait. Every day that funding is delayed is another day I don't work. Every day wasted on redoing the same old studies, retracing the same old research steps, repositing the same worn-out theories, is another day that my son lies in bed in intense pain.

The change has got to happen now for us and for millions like us. We need you to use your knowledge and positions now to make that change happen.

Not only is the link of ME/cfs to MLVs strong, not only has the research been confirmed, not only has the new research strengthened the initial evidence, not only has XMRV been proven susceptible to antiretroviral drugs already approved in treating HIV infection, but beyond all that people who have been able to do so have tried HAART and similar antiretroviral treatment and they have improved.

Can you imagine functioning for years and years at 40% of normal activity? Think of any action you feel responsible to take, anything you enjoy doing, anything you dream of doing, and cross it off your to-do list. Wash dishes? Take a vacation? Make a difference in your community? No, no, and no. Lie down and endure the pain. Can you imagine living like that?

If someone said that a drug already in use for other illnesses might restore you to 80% activity in mere months, would you not wish to try that drug? Or would you soberly insist that clinical trials and prescription approval be delayed until the pathological mechanism of the retrovirus was fully

understood and independently confirmed in double-blinded studies at multiple research facilities and brought to publication and subjected to further debate?

Suppose it was your child lying in the next room, bravely trying not to worry you by moaning or complaining? I am sure you have both the compassion and the imagination to see the need. If I were well enough I would be standing right in front of you today making this demand on behalf of my child, myself, and all of us many millions, if that would make any difference. But you don't need us to stand in front of you. You know what we are all saying to you, and to our doctors, and to the press, and to our elected representatives.

Fund Clinical Trials Now.

Thank you for your attention to my brief appeal: I hope to give my son good news after your committee meets.

Sincerely,

Kathleen Fatooh