

Testimony of Jamie Deckoff-Jones MD
CFSAC
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To whom it may concern:

I am a 56 year old emergency physician. I have been diagnosed with CFS, chronic Lyme Disease and atypical MS. My 20 year old daughter has been diagnosed with CFS and chronic Lyme Disease. I have been ill for 16 years and disabled for 6. My daughter has been ill for 7 years and disabled for 4. In the last few years, I have almost died twice and my daughter has been hospitalized for cerebral vasculitis. My husband has been ill for 7 years and is functional. My 15 year old son is clinically healthy.

In October of last year, I read the Mikovits paper in Science. It was immediately apparent to me that our illness was of retroviral origin. In February, my daughter and I tested positive for XMRV by culture. We were both almost housebound at that time. With the help of a compassionate family doctor and the guidance of an experienced AIDS doctor, we started the three antiretroviral drugs that tested in vitro against XMRV in the Singh study. Six months later, my daughter has started community college and I am planning a return to part-time practice. As always with clinical medicine, there are confounders, but I do not think it possible that we have not been helped by antiretroviral therapy.

Because the patients have no help, I started a blog to share our experiences with treatment and my clinical ideas. The response has been enormous. My email is filled with stories of unbelievable pain, neglect and abuse. The wasted lives and wasted talent are a national disaster. Instead of contributing, a staggering number of people are unable or almost unable to care for themselves.

Since CFS patients don't die from their disease for a very long time, there is a tendency to feel that there is no hurry. Good science takes time after all. But it is a progressive disease. There are a staggering number of patients who are too sick to wait. They need compassionate care. They've been denied basic care, even common decency, for decades. It's been a year since the association between XMRV and CFS was elucidated. Scientists say causation has not yet been demonstrated. I say it should be a clinical assumption at this point. As a physician, it's obvious from the stories and family histories of the patients contacting me. Where have the epidemiologists been all this time? I am an emergency doctor and this is an emergency!

To me, it's a miracle that existing safe drugs may be effective. It is a travesty that clinical trials have not yet begun. It brings shame on the medical profession that doctors are unable to connect the dots. If there was a hurricane or an earthquake, everybody would be rushing to help. Even if all resources are immediately mobilized, many will be lost. The patients have very advanced disease. It is beyond a disaster.

New babies are being born with it every day. Is it possible that AZT in pregnancy will prevent it, as it does HIV? Why is nobody trying to find out?

The WPI has single-handedly made things happen for patients. Why are they not funded? They are a tiny non-profit. They have handed the world the answer on a silver platter. Is our government ever going to step up to the plate?

Sincerely,

Jamie Deckoff-Jones MD