

Testimony

Anonymous

Committee Members,

I have been ill with a neuro-immune disease for nearly twenty five years. My illness began with an acute case of non-EBV mono from which I never fully recovered. At the time 2 other family members became sick as well one lost his their life to cancer the other has been diagnosed with 2 separate and very rare lymphomas 5 years apart. Our symptoms were classic for a disease my doctor called a viral syndrome. Those symptoms included painful swollen lymph nodes, night sweats, severe headaches, low grade fever, nausea, and shingles like nerve pain in my spine, low blood pressure, hypoglycemia tachycardia, non-refreshing sleep, a profound weakness and loss of energy. Cognitive problems included difficulty concentrating and difficulties with short term memory. Before becoming ill I had been an A student with almost perfect attendance, afterwards, I could no longer stay well enough to attend a full day of class or study much on my own. Soon I became completely homebound, unable to shower or even get out of bed without help. At various times in my illness I have been unable to walk and have been wheel chair bound. I now suffer from seizures and can no longer drive or even fly in an airplane to visit relatives for holidays. My life has become severely compromised.

Use of an experimental therapy during the 1990s gave me a few years of better health. During that period of time I was even able to work several hours a day. While on the drug, I met and married a man who was healthy, worked full time, and leading a very active life. Over the course of 3 years of marriage, my husband became ill with many of the same symptoms that I experience. He and I have both tested positive for XMRV by viral culture and antibody testing. Unfortunately my partner is now picking up opportunistic infections such as EBV, HHV-6, and is sick constantly. Anyone that suggests my disease is not transmitted, from person to person, is fooling themselves and the American public. I know of many couples with a similar story, in which one individual was sick at the time of their meeting then some time after, the other became ill. If this retrovirus is spread by close contact or body fluids, as has been suggested by recent animal studies, then certainly it can be spread through blood transfusions.

I am pleading with those of you who are charged with the safety of our nation's supply of blood and funding critical research to take action now by requiring the testing of all blood donors for XMRV and its variants and keeping XMRV positive blood out of the nation's blood supply. I also ask that infectious disease doctors become aware of the severity of M.E. and begin clinical trials with antiretroviral therapy for those patients that meet the Canadian Criteria of M.E. I chose to remain anonymous out of fear of losing my health insurance admitting that both my partner and I have a retrovirus has been life altering and only our family knows. We are asking you to help us get well so we can go back to work, our social and family life and care for each other and hopefully have a family of our own someday.

Sincerely yours,
Anonymous