

## **Testimony**

### **Karen Ravitz**

I am 50 yr. old Wife and Mom of 2 amazing college age kids. For the past 16 years I have suffered with Myalgic Encephalomyelitis. I also have Lyme, Fibromyalgia, and am being tested for XMRV through the Whittemore Peterson Institute. My family and I suffer greatly as a result of this disease...my children have lost their mother for most of their lives.

Finding knowledgeable doctors to treat AND accept medicare is a rare find! I've seen no less than 15 doctors in 4 states...a number of whom have only suggested an increase in antidepressants. Thank you CDC for perpetuating the notion that CFS stems from childhood abuse/trauma...NOT! It is beyond humiliating!

Not to mention the enormous expense of supporting my illness!!! I have been on SSD since 2001 and my husband is been in and out of work, due to the economy. He is self-employed; health insurance, before co-pays and deductibles for our family of four is about \$2,000 a month! It costs me over \$600/month just for medicine and supplements alone. Needless to say, with 2 kids in college we are truly struggling financially.

My previous employer, Prudential, has harassed and demoralized me in my fight to continue long term disability. I have lost income, health and life insurance that I am entitled to after 12 years of dedicated employ. I feel robbed on so many levels!

We need treatments for this disease now. My life is slipping away. I cannot afford Ampligen trials. I have a caring ME/CFS doctor, but can only see him twice a year as he is in NY and I am in NC. He is not able to offer me more than methylation support and antivirals, which are far from adequate.

Last year I lost a sweet friend from ME/CFS complications after a 10 year battle with this disease. Becky Childs was 23 years old and just been accepted to NC State University. She could have had her whole life ahead of her. Instead she left a grieving family. Mainstream doctors were ignorant and she needlessly died as a consequence.

I am asking that HHS finally listen to the CFSAC recommendations:

1. Develop a national research and clinical network for ME/CFS (myalgic encephalomyelitis/CFS) using regional hubs to link multidisciplinary resources in expert patient care, disability assessment, educational initiatives, research and clinical trials. The network would be a resource for experts for health care policy related to ME/CFS.
2. Engage the expertise of CFSAC as HHS moves forward to advance policy and agency responses to the health crisis that is ME/CFS.
3. Adopt the term "ME/CFS" across HHS programs.

I am requesting that at least \$150 million be moved over to ME/CFS biomedical research, as we have over 100 million sick, leaving us being funding at less than \$3.64 per patient! We are at the bottom of the pile picking at crumbs compared to other serious, disabling diseases.

I am also begging that the Whittemore Peterson Institute be awarded a substantial grant to move the XMRV/MLV science forward. Based on my family history, I believe in the retroviral connection to ME/CFS, autism and cancers. Here is a list of my family's illnesses:

Me (Age 50)

Disabled with ME/CFS/FMS since 1995, endometriosis, ovarian cysts, chronic allergies, asthma, sinus problems, TMJ, PTSD, anxiety, skin cancer, Lyme and the list goes on...

My Daughter (Age 21)

FMS, chronic allergies, asthma, sinus problems, recurrent pneumonia, chronic pelvic pain (possible endometriosis), anxiety disorder, GERD

My Son (Age 18)

Severe ADHD, ODD, allergies, asthma, sinus problems, IBS

My Husband (Age 56)

Depression and anxiety

My Brother (Age 47)

CANCER (squamous cell in lymph node, recently underwent chemo and radiation at Sloan-Kettering; skin cancer), allergies

His Daughter (my niece, Age 7)  
Petit mal seize disorder, allergies, asthma

My Sister (Age 51)  
Chronic pelvic pain before menopause, early menopause, skin cancer, MDD,  
allergies, asthma

Her Daughter (Age 25)  
Fibromyalgia, suspected ME/CFS, asthma

Her Other Daughter (Age 23)  
Allergies, asthma, pre-cancerous skin lesions

My Mother (Age 72)  
Fibromyalgia, skin cancer, allergies

My Step Father (Age 81)  
CANCER (currently being treated by Sloan-Kettering for non-small cell  
lung cancer, skin cancer)

My Father (Deceased at Age 74)  
Emphysema, myeloproliferative disorder (pre-leukemia) and skin and  
prostate cancer

We can't wait for Dr. Lipkin's study to be complete for answers. We need clinical  
trials and treatments now!

Thank you to all the ME/CFSAC Committee members for your devotion and  
support.

Sincerely,

Karen Ravitz