

Testimony

Peg Danek

My name is Peg Danek. I first fell ill May 8, 2010 with a virus that I caught from my son. He recovered and I did not. Before I became ill I worked full time for MIT Lincoln Laboratory, took care of my family and was in the middle of training for my first competitive season as an adult figure skater. I had already won two medals. Now, I am mostly housebound and occasionally bed bound. In order to get a diagnosis:

I had 35 Office visits, 4 Phone consultations and countless emails
I saw 9 Doctors, 3 Med students, 1 Psychologist and 1 Psychiatrist.
I gave >50 Vials of blood (I lost count after 30), had 2 Cortisol saliva tests,
2 Urine tests, 1 MRI of brain, 1 CT scan of abdomen, 2 Ultrasounds, and
~12 X-rays

After eleven months of doctor visits and tests what did they find?
Low B12, Low D, Elevated inflammation markers, and Suboptimal thyroid
function and minor impaired cognition.

I live near Boston so I have access to the finest medical facilities on the planet. During the eleven months that I tried to get diagnosed as soon as a specialist had run all their tests I was foisted off on the next specialty. I saw a virologist, infectious disease specialist, an endocrinologist, a neurologist, a psychologist, psychiatrist and two rheumatologists. I was passed around like a hot potato. No one wanted me as their regular patient. Although I met the CDC criteria for CFS since last October not ONE doctor wanted to go on record with a diagnosis of CFS. This is Boston! Apart from Dr. Komaroff, to whom you have to apply to become a patient, there are no mainstream doctors that want to diagnose or treat CFS.

Why is this? There is no biologic marker that can be used for definitive diagnosis and there is no money available for CFS research! Due to the lack of an accepted biomarker they are too scared of insurance companies and lawyers to go on record with a CFS diagnosis. Also, they will not waste their limited resources on an illness that has no funding. In order for them to have a thriving career they must concentrate their resources on illnesses that have adequate research monies available for them to be able to do cutting edge research, publish papers, develop drugs and treatment protocols, in the hopes that they will become the next Crick

and Watson. They don't want to waste their time involved with legal cases trying to prove that I'm actually sick when there is no proof.

What does this mean to me as a patient?

It took 11 months to get a diagnosis.

I had to go to a holistic health practitioner to get that diagnosis.

I still haven't heard back from Dr. Komaroff even though my doctor sent him a letter over a month ago.

I have no rheumatologist that wants me as a regular patient.

My long term disability insurance company turned down my application due to lack of medical evidence.

Because of that I lost my job and health insurance for my entire family.

Social security is sending me to a psychologist due to lack of medical evidence and there is a good possibility that they will turn down my application as well.

Where does that leave me? I have no income and no medical insurance. Now that I have a diagnosis I have no way to pay for treatment. And why is this?

THERE IS NO FUNDING FOR RESEARCH. THERE ARE NO BIOLOGIC MARKERS THAT ARE ACCEPTED BY THE CDC AS DIAGNOSTIC TOOLS FOR CFS.

So I am stuck in my bed with no hope of treatment never mind a cure. I am dependent upon others for food, housing and medical care. All because of a lack of funding.