

Testimony

Jacqueline Mann

Dear Sir/Madam

My name is Jacqueline Mann I have had M.E for twenty five years...I as many others contracted the disease from a mystery illness, one day I was a healthy, sporty, very active mother of a three year old, then got sick with a violent headache and flu like symptoms this has never left me.

My life as a mother was virtually over everything was a struggle, I feel not only has my life been ruined by M.E but also my daughters, I have definitely lost the best years of my life, from age twenty eight up to now I am fifty three, I would so like to just get a few years of normal life before I pass away. Why won't anyone help us, what is the big secret? I know that sounds paranoid, but from my side of the fence that's how it feels.

Excuse the spelling and punctuation mistakes, but that is how it is when you live in a fog.

You have heard personal stories from so many others with this crippling disease over the years and still nothing is being done to fund research into the cause, to offer proper treatments, hope and a cure. The only hope we have is from the Whittemore Peterson Institute who are researching this disease. Why are they not receiving funding? Patients want the WPI to receive funding.

Patients here in the UK are offered nothing but psychological interventions, CBT and graded exercise therapy, which can do so much harm and damage. We want psychologists taken out of all research and discussion into this disease. We want researchers like Judy Mikovits, Leonard Jason, Nancy Klimas, Jose Montoya to receive funding and backing. They understand this disease better than most. They get it.

We are mistreated, ridiculed and ignored by the medical profession and governments worldwide. We are ridiculed by the general public who do not understand this disease or see us sick as it is a hidden illness, we suffer behind closed doors unable to have visitors or talk on the phone without severe consequences afterwards. We suffer from extreme post exertional malaise after the slightest effort from brushing out teeth, to washing ourselves. Many of us live on

painkillers, sleeping medications. We don't want medications that mask our symptoms, we want medication that will get us well again, we want ampicillin or other medication that will allow us to function normally again.

We want to be seen by neurologists, immunologists, endocrinologists.

We want public awareness, we do not want to be accused of "being lazy" or "just tired", we know everyone gets tired, "tired" or "fatigue" does not even come close to what we experience. The name of Chronic Fatigue Syndrome is ridiculous and hated by everyone who has this disease, We want a name change.

We want the Canadian Guidelines, proper biomarkers established, proper diagnosis, this disease is ridiculously overdiagnosed due to the fuduka guidelines and doctors being unable to tell the difference between burnout, post viral fatigue and M.E./CFS. We want education and training given to medical students, doctors and nurses alike.

We are battling and surviving just getting through each day and night, we have lost friends to this disease. In the UK we lost Sophia Mirza, a young 32 year old woman to this disease, see <http://www.sophiaandme.org.uk/summary.html>. We lost Lynn Gilderdale, who suffered for 17 years and could not battle on any longer and took her own life, see <http://www.dailymail.co.uk/femail/article-1376605/Kay-Gilderdale-How-I-helped-darling-daughter-die.html#ixzz1JRr2Y3BI>

"When her body was examined by the pathologist who specialised in M.E., he discovered 'dorsal root ganglionitis' - infected nerve roots - and nodules of Nageotte, which are little tombs of dead cells, in her spinal cord.

These would have caused her terrible pain and sensory nerve damage.

They found similar cells in the body of Sophia Mirza, an M.E. sufferer who died in 2005 at the age of 32, and I believe also in other sufferers."

Lynn and Sophia both suffered at the hands of medical professionals who did not believe they were sick, they were abused and ridiculed, adding to them and their families suffering, accused of pretending to be sick, autopsies proved they WERE sick. There are others Casey Fero, Alison Hunter, Aylwin Catchpole and nearly myself who resorted to taking an overdose after losing hope. How many more autopsies and deaths will it take for governments and the medical authorities to act? Enough is enough, we cannot go on anymore listening to the same discussions going on from patients begging you for funding research, for proper treatments, to find the cause of this disease.

I beg you to please act now and save one more person from becoming ill with this terrible disease or resorting to taking their own life as a way to end the pain and suffering.

Thank you

Regards,

Jacqueline Mann