

Public Comment

Jadwiga Lopez-Majano

When our grandsons became ill with ME/CFS, our lives changed completely.

We were both retired when they were born and therefore free to spend a lot of time with them and their parents, even though they lived in Oklahoma and we in Chicago.

We visited back and forth, explored state parks together, escaped to Acapulco in the winter, and enjoyed vacations in Massachusetts, Michigan, Colorado and Illinois. We, of course, became very familiar with the Children Museum in Chicago, as well as enjoying The Art Institute, The Field Museum, and others, the zoos and the Botanic Garden. There were trips to Europe: to visit friends, family and sites in Italy and to attend special events with the family in Spain.

Our 50th anniversary gift to each other was to be a trip to Greece for all of us. It was all planned, reservations made, when we found out that Matthew was too incapacitated because of ME/CFS to travel. That was 7 years ago. I still have the file of arrangements, itinerary... **Unused.**

Since ME/CFS imposed itself on Alexander and Matthew, I see the boys (now young men) only once or twice a year and only in their home. They cannot fly and it is too far and too exhausting for them to travel by car. I no longer get spontaneous phone calls with news about school, swimming meets, new games, etc. because they had to leave school, give up swimming, and because conversation is now so difficult and taxing for them.

I know very little about the books they read, the political concerns they have, what they would like to do with their lives, because talking is physically painful. There are no more walks, visits to friends, trips to museums.

Alexander and Matthew's lives have been **shoved** into an abyss by ME/CFS.

As their grandmother, I am deeply concerned with the prolonged lack of serious attention given to ME/CFS and the lack of serious funding for ME/CFS research by DHHS agencies. And I am appalled that this has been going on since before Alexander and Matthew were even born!

Things like the inexcusably small amounts of funding for ME/CFS research are shameful. It is SHAMEFUL that during the average length of illness for a patient with ME/CFS NIH spends only \$240.00 per patient. That's what \$6.00/year/patient over 40 years works out to.

Contrast that with NIH spending on Lupus and MS both of which are similarly disabling illnesses but are less prevalent than ME/CFS. (see attached)

Over the course of the average length of illness for a person with Lupus, NIH spends \$3,500.00 per patient.

And for MS, NIH spends \$9,900.00 per patient over the course of the average length of illness. (see graph)

This MUST change!

I have read the joint letter of concern submitted to Secretary Sebelius, Dr. Koh, Dr. Lee and the CFSAC, and signed by 14 organizations and 19 individuals.

I too endorse this letter of concern.
I want to reinforce points made in that letter.

The ME/CFS strategic plan must be a coordinated and fully funded effort to finally *solve* ME/CFS.

The ME/CFS strategic plan must resolve definitional and classification confusion and ensure that research is done using a definition that appropriately identifies patients.

The ME/CFS strategic plan must provide a fair share of research funding, focused on biological pathologies, biomarkers and treatment and it must remove all barriers to progressing such studies.

The ME/CFS strategic plan must ensure appropriate education of the medical community and must significantly improve the CDC 'CFS' website so that it better describes the disease.

The ME/CFS strategic plan must accelerate the FDA pipeline for ME/CFS treatments.

The ME/CFS strategic plan must result in easily accessible treatments that help patients, caregivers, medical professionals (and everyone else) improve the quality of patients' lives while decreasing disability and sickness.

The ME/CFS strategic plan must start NOW!