



# **New Jersey Chronic Fatigue Syndrome Association**

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# **New Jersey Chronic Fatigue Syndrome Association**

**NJCFSA has been serving ME/CFS patients since 1995 by providing --**

- \* Support groups**
- \* Website and social media**
- \* Help line**
- \* Medical conferences**
- \* Physician and Attorney referrals**
- \* Public policy and patient advocacy**
- \* Scholarships for graduating HS Student with ME/CFS**
- \* Medical student scholarships**

## **FIRST, patients need TREATMENTS!**

Through the approval of new drugs and repurposing of existing drugs now used off label for ME/CFS.

The FDA needs to hold a second Drug Development Workshop with drug companies specifically invited to participate.

Invite those companies which have developed drugs now being used by clinicians off label or which are in the FDA's pipeline and the clinicians who are expert in the disease.

Such a drug development workshop is not now planned. Please plan one early in 2014 to move drug development forward.

## **SECOND, patients need KNOWLEDGEABLE DOCTORS!**

**There is almost no medical school training for ME/CFS diagnosis and treatment now in the U.S.**

**An appalling ignorance and bias exists among doctors untrained in ME/CFS.**

**“...CFS-related instruction, treatment, and especially research is at an unacceptably low level within the medical education community.” \***

\* Universal Journal of Public Health 1(4): 177-179, 2013 DOI: 10.13189/ujph.2013.010404.

## **How can the DHHS improve the doctor and doctor-information shortage?**

**Create at least five Centers of Excellence for diagnosis, treatment, and medical education of ME/CFS.**

**Five regional Centers of Excellence were recommended by CFSAC from 2004- 2011.**

**None were set up.**

**Bring the CDC website up to date.**

**Remove the Toolkit from the CDC website**

(recommended by CFSAC June 2012).

**Remove the CME course from the website.**

Both are inaccurate, incomplete, and harmful.

**Replace with the IACFS/ME PRIMER.**

## **The NIH needs to greatly increase funding for ME/CFS.**

- ~ Only \$5.00 per patient per year is allotted by NIH for ME/CFS research and treatment studies - \$5 million total.
- ~ Over \$ 3 BILLION is allotted per year for HIV/AIDS. There is approximately the same number of patients in the U.S. as have ME/CFS.
- ~ \$116 million for multiple sclerosis, with only half as many patients as ME/CFS (about 500,000).
- ~ \$84 million is provided for anthrax, a disease with very few patients per year.

## **Suicides are rising among ME/CFS patients.**

- ~ There are NO drugs approved by the FDA.
- ~ There is little to no training in medical schools about ME/CFS.
- ~ There are no regional Centers of Excellence for diagnosis and treatment.
- ~ There is almost no funding for research into treatments and causes.

**All of this = NO HOPE for patients, who must cope alone and very often with almost no money and no support.**



**The Department of Health and Human Services,  
and particularly the NIH and CDC,  
must begin to take this  
disease very seriously.**

**Provide what the patients need,  
not what the HHS and its departments need.**