

UNJUST UNDERFUNDING:

THE SEVERE FINANCIAL NEGLECT OF MYALGIC ENCEPHALOMYELITIS
CHRONIC FATIGUE SYNDROME



WHAT IS ME/CFS?

ME/CFS or Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is a severely debilitating condition that affects millions of people across the world and can cause significant impairment and disability, in many cases more so than victims of Multiple Sclerosis and end-stage renal disease (Beyond ME/CFS: Redefining an Illness, 2015).

Nearly 25% of the 836,000-2.5 million Americans who suffer from this illness have been put out of work at some point, costing the U.S. economy an estimated \$17 to \$24 billion per year.

The disease often drastically alters the lives of patients permanently, with chances of recovery exceedingly rare. It is more prevalent on women, and has many symptoms including “profound fatigue, cognitive dysfunction, sleep abnormalities, autonomic manifestations, pain, and other symptoms that are made worse by exertion of any sort”

THE INVISIBLE SYMPTOMS OF ME/CFS

- FATIGUE
- ANXIETY
- CONFUSION
- DEPRESSION
- LOSS OF MEMORY
- DISTURBED SLEEP
- LOSS OF CONCENTRATION
- UNEXPLAINED MUSCLE AND JOIN PAIN



However, for many years ME/CFS has faced many criticisms, disbelief, and hostility in the medical community. This is all due to the once popular belief being that ME/CFS is a psychiatric/psychological issue, creating a stigma resulting in a severe lack in patient care.

These beliefs have stemmed from studies such as the PACE Trial published in February 2011, claiming “Exercise and psychotherapy...can significantly improve and sometimes cure [ME/CFS].”

These findings have been found to be incorrect. In fact such treatments worsen patients’ conditions and have had lasting negative impressions. (PACE Trial, 2018)

THE ISSUE

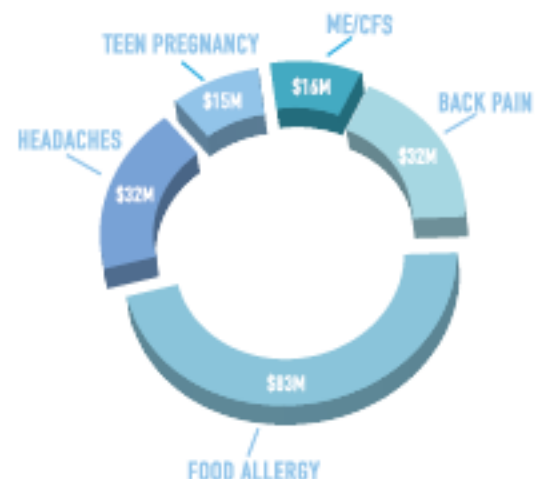
Despite the fact that this public health issue is extremely widespread both globally and in the U.S., there still remains a severe lack of funding.

ME/CFS RECEIVES 1/25 OF THE FAIR AMOUNT OF FUNDING RELATIVE TO ITS DISEASE BURDEN

Numbers released by the National Institute of Health validate just how under subsidized research for ME/CFS is, with spending for ME/CFS averaging just \$5 million a year between 1995 and 2014.

In 2018, \$83 million has been dedicated to food allergies by the NIH, while only \$16 million was dedicated to ME/CFS.

There are many more examples of diseases with much smaller disease burdens (the impact as measured by financial cost, mortality, and morbidity) receiving severely unproportional funding as compared to ME/CFS, as well as illnesses with disease burdens similar to that of ME that receive considerably larger amounts of financing. (NIH, 2019)



Data obtained from NIH Categorical Spending Report, 2018

Although ME/CFS has been found to cause more impairment and debilitation than MS and is estimated to be over twice as prevalent in the U.S., it still garners only 1/7 of the financial support.