

**OPEN MEDICINE FOUNDATION
OMF**



Open Medicine Foundation ®

ME/CFS

**Myalgic Encephalomyelitis/
Chronic Fatigue Syndrome**

**A MAJOR PUBLIC HEALTH
CRISIS**

**THAT MOST PEOPLE KNOW NOTHING
ABOUT...**

**This could happen to
anyone at anytime**

**And...
No diagnostic test
No effective treatment
No cure**

Whitney: Casualty of ME/CFS
A View of ME/CFS

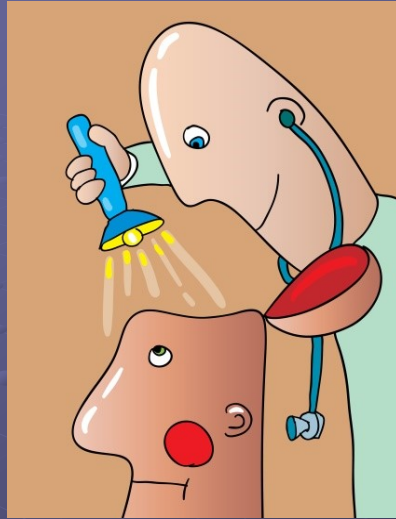


**From an active award-winning photographer...to
sick with ME/CFS...bedridden...in a dark room**

Major Symptoms: Institute of Medicine (2015)

- **Profound fatigue & inability to carry out normal daily activities**
- **Worsening of symptoms after physical, cognitive or emotional effort**
- **Unrefreshing sleep**
- **Cognitive impairment**
- **Symptoms worsen when a person stands upright**





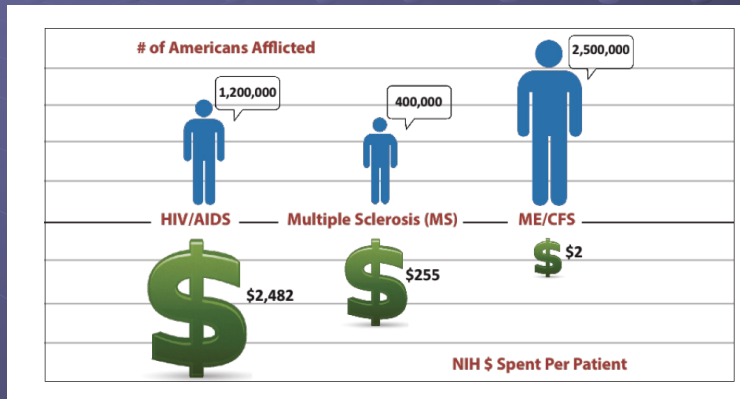
ME/CFS is not in the head!

Skyrocketing Numbers

- **Up to 2.5 million USA, 8-20 million worldwide**
- **> 80%: Unable to work or attend school**
- **> 25%: Entirely bed or house bound**
- **> 90%: Not correctly diagnosed**
- **Huge overlap with Fibromyalgia, Autism, Chronic Lyme, Gulf War Illness**

ME/CFS Research Poorly Funded

- NIH: \$2 Per patient per year vs MS \$255pp
- One of the lowest \$ for any major disease
- Further \$ cuts proposed



**OPEN MEDICINE FOUNDATION
OMF**

**THE GAME CHANGING
SOLUTION**



OMF Goals

Find a diagnostic tool, effective treatments, prevention strategies and ultimately a cure

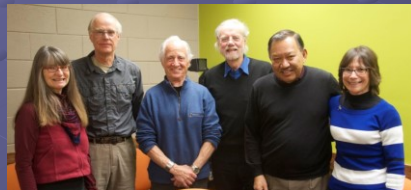
Share & Educate

A Unique OPEN Model & Approach

- **Prestigious Scientific Advisory Board:**
 - **Director: Ronald W. Davis, PhD:**
 - ❖ **Director, Stanford Genome Technology Center**
 - ❖ **“One of Today’s Greatest Inventors” (Atlantic Magazine, 2013)**
 - **World-renowned researchers including:**
 - ❖ **3 Nobel Laureates**
 - ❖ **6 National Academy of Sciences’ Members**



SAB IN ACTION



Accomplishments Since Starting OMF (2012)

- > \$6.2 million: Raised for Research
- Multiple Research Projects in Progress
- Physician/School Education Project (2017)
- Guidestar: **Platinum status (2016)**
- Great Nonprofit Designation: **Top-rated charity (2015 & 2016)**
- End ME/CFS Worldwide Tour 2017



She's obviously feeling very bad today.
We'd better visit her another time.



**Time to take a deep
breathe and relax!**

RESEARCH UPDATE

OMF END ME/CFS PROJECT

OMF End ME/CFS Project

- **Severely ill Big Data Study**
- **Metabolomics Validation & Genomics Study**
- **SGTC Inexpensive Disruptive Technologies**
- **Status & Preliminary Findings**

Severely ill ME/CFS Big Data Study Status

- **Goal:** Identify molecular signals & defects
- **Methods:** Profiling of DNA, RNA, proteins, metabolites & microbiome
- **Results:** No clear signals yet, testing still in progress. Evidence of reduced metabolism observed
- **What's next:** Continue analysis; share results openly as resource for research & clinical communities

Metabolomics Validation & Genomics Study

Robert Naviaux, MD PhD:

“Our findings are consistent with the notion that ME/CFS is a coordinated hypometabolomic state (reduction in several key metabolites).”

Ronald W. Davis, PhD:

“This publication is a landmark in ME/CFS research. It is the most important and ground-breaking study of ME/CFS to date.”

What is Metabolomics?

Measure & study of metabolites = small molecules (sugars, amino acids, lipids) present in cells, blood, urine & stool



“I believe that at the root of ME/CFS is a treatable metabolic syndrome.”

Robert Naviaux, MD, PhD, March 2017

“I believe that the primary, genetic mitochondrial diseases are much harder to treat than ME/CFS will end up being. The majority of sufferers of ME/CFS probably don't have physical damage to their cells or mitochondria. Instead, their cells and mitochondria are working abnormally because they are under abnormal instructions that block the normal signals for healing. If these cell signals can be changed by new therapy, then healing and recovery might be possible.”

Metabolomics Validation & Genomics Study

- **Goal:** Verify hypometabolism & identify genetic factors (SGTC)
- **Methods:** Genome (DNA) sequencing & metabolomics
- **Results:** Suspicious genetic mutations identified:
 - Different symptoms in different patients may be explained by genetics
- **What's next:** Study function of genetic mutations & expand to additional patients

**Stanford**
MEDICINE

Genome Technology Center

Inexpensive Disruptive Technologies

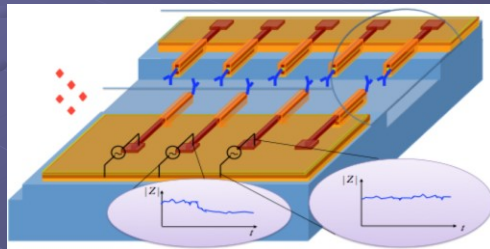
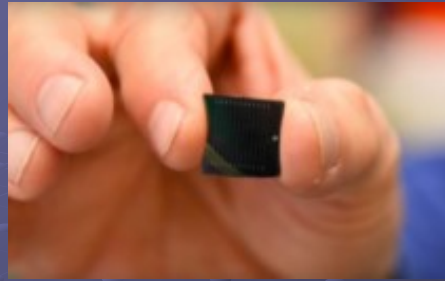
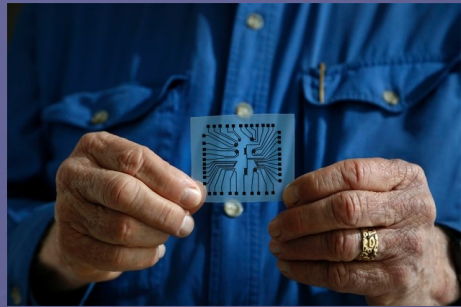
Devices in development: “lab-on-a-chip”

- **Nanofabricated cubes: 2500 Electrodes measuring electrical resistance**
- **For diagnostic purposes: ME/CFS cells stressed with salt could not recover as well as healthy cells**

**Stanford**
MEDICINE

Genome Technology Center

- **Ability to test 100 patients at once**
- **2D Printer to produce cheaply: < 1 cent**
- **Test many potential treatments as quickly as possible: FDA approved drugs**



Nanoneedle biosensors to detect cells, molecules of interest via electrical signals

Stanford MEDICINE | Genome Technology Center

Stanford MEDICINE | Genome Technology Center

Interesting Findings

- **Problem may be in the serum:**
 - Good news, we should be able to find it
 - If in the serum, it may be easier to cure.
- **Focus:**
 - Are there component(s) released in the serum that could be causing the problems?
 - We have some good ideas already

OMF End ME/CFS Project

Fascinating Preliminary Results

- **ME/CFS = Molecular disease**
- **Problems in citric acid cycle that generates almost all energy; problems burning glucose**
- **May be triggered by environmental stressors**
- **SGTC technologies: Diagnostics & treatments**
- **Big Data & technology WILL unravel ME/CFS**

Dr. Ron Davis:

**“I think we can cure this illness.
We are getting close enough to
understanding the mechanism.”**

**“Treating it would be OK, but
I want to cure it!”**

Breakthroughs have been made.

Now we need to step this up

to find a cure.

With significant funding,

we can do this.

What can YOU do?

- Join a community
- Spread HOPE
- Fundraise for research
- Crowdchange
- Take care of a loved one
- “Like” OMF Facebook
- Sign up to the OMF e-newsletter
- HealthRising.org
- PhoenixRising.me

We need your help!



JOIN TEAM OMF

Join us on Social Media
@openmedf



USE OUR HASHTAGS.
#ENDMECFS #OMF

DONATE NOW
Give a Reason for Hope



Host an Event in your
Hometown



Become A Volunteer



Create a page to honor a friend or loved
one and invite others to donate



Share your Friday Story. .



Shop and Sell
Designate OMF

TEAM OMF is working together to end ME/CFS. Learn about how you can help..
WWW.OPENMEDICINEFOUNDATION.ORG



WINNER
sundance
2017

SKSW 2017
FILM FESTIVAL

OFFICIAL SELECTION
CPH:DOX
2017

OFFICIAL SELECTION
hotdocs
2017


UNREST

Directed by Jennifer Brea


An award-winning documentary on a mission to:

- Grow a grassroots movement advocating on behalf of ME*
- Educate the medical community*
- Encourage more scientists and funding to the research field*

Contact impact@unrest.film and learn more at www.unrest.film.



Get Connected & Get Involved



#MEAction is a global, grassroots advocacy community that supports, connects and empowers people living with ME, their families, and allies.

To get connected and get involved, email joinus@meaction.net,
www.meaction.net

It's Time to Move Forward Together



Join Team OMF to Find Answers!



Open Medicine Foundation OMF

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