

OPEN MEDICINE FOUNDATION (OMF) ®



A 501(c) 3 non-profit organization

www.omf.ngo

ME/CFS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

**A MAJOR PUBLIC HEALTH CRISIS
THAT MOST PEOPLE KNOW NOTHING
ABOUT**

**ME/CFS could strike anyone
at anytime...**

No diagnostic test

No FDA-approved treatments

No cure

Centers for Disease Control and Prevention (CDC), 2006

“Level of disability for ME/CFS is comparable to MS, AIDS, end-stage renal failure and other well-known very severe medical conditions.”

Dr. W. Reeves, Former Chief Viral Diseases

National Academy of Medicine (Institute of Medicine), 2015

“ME/CFS is a serious, chronic, complex and multisystem disease that frequently and dramatically limits the activities of patients and in its severe form can consume the lives of those whom it afflicts.”

National Institutes of Health (NIH), 2017

“We recognize and empathize with the suffering experienced by people with ME/CFS and their frustration that so little is known and so little research has been done to find answers. We aim to change that.”

Dr. Francis Collins, Director

What Does ME/CFS Feel Like?

Main symptoms:

- Debilitating fatigue
- Post-exertional malaise (worsening of symptoms after physical, cognitive or emotional effort)
- Unrefreshing sleep
- Cognitive impairment/brain fog
- Incapacitating migraines & dizziness
- POTS: Orthostatic intolerance
- Widespread pains & chronic infections

CHRONIC FATIGUE SYNDROME:

“THINK OF THE
WORST FLU YOU
HAVE EVER HAD,
TIMES 10,
WITHOUT END...”

Whitney: Casualty of ME/CFS



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

Skyrocketing Societal Impact

- **Up to 2.5 million in USA, 8-20 million worldwide**
- **> 80%: Unable to work or attend school**
- **> 25%: Entirely house-bound**
- **> 90%: Not correctly diagnosed**
- **Huge socio-economic costs: > \$24 billion in medical/productivity**
- **Similarities to Fibromyalgia, Autism, Chronic Lyme, Gulf War Illness**
- **Underfunded & underresearched: ME/CFS & related chronic diseases**

H  **P** **E**

OpenMedicine
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**THE END
ME/CFS
PROJECT**

OPEN MEDICINE FOUNDATION

THE GAME CHANGING SOLUTION



OMF's Goals

**Find a diagnostic tool, effective treatments,
prevention strategies & ultimately a cure**

Share & Educate

Open Medicine Foundation (OMF) since 2012

- > \$8.0 million raised for Research
- **Multiple Research Projects in Progress Worldwide**
- **Physician Education & School Accommodations Projects (2017)**
- **Physician Data Project (2017)**
- **Research Interns at Stanford and Nova Institute (2015,2017)**
- **Guidestar: Platinum status; Great Nonprofit Designation: Top-rated**
- **End ME/CFS Worldwide Tour 2017: Outreach > 90 countries**

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**

SCIENTIFIC ADVISORY BOARD



THE END ME/CFS PROJECT

OMF
ME/CFS
Scientific
Advisory Board

3 Nobel Laureates & 6 National Academy of Sciences Members



Ronald W. Davis, PhD
Sci. Advisory Board Director
Member of National
Academy of Sciences



David S. Bell, MD



Paul Berg, PhD
Nobel Laureate
Member of National
Academy of Sciences



Mario R. Capecchi, PhD
Nobel Laureate
Member of National
Academy of Sciences



Mark M. Davis, PhD
Member of National
Academy of Sciences



**Øystein Fluge,
MD, PhD**



Maureen Hanson, PhD



H. Craig Heller, PhD



**Andreas M. Kogelnik,
MD, PhD**



Olav Mella, MD, PhD



**Robert K. Naviaux,
MD, PhD**



**Baldomero M.
Olivera, PhD**
Member of National
Academy of Sciences



**Ronald G. Tompkins,
MD, ScD**



James D. Watson, PhD
Nobel Laureate
Member of National
Academy of Sciences



Wenzhong Xiao, PhD

Biochemistry
Bioinformatics
Biophysics
Cellular Metabolism
Clinical Care
Data Analytics
Drug Development
Exercise Physiology
Genetics
Immunology
Microbiology
Molecular Biology
Neurobiology
Neuroimmunity
Public Health Policy
Oncology
Pediatrics
Surgery
Trauma
Zoology

Community Symposium on the Molecular Basis of ME/CFS
Sponsored by Open Medicine Foundation (OMF)



The banner features a background image of a microscope. The text is overlaid on the right side of the image. At the bottom, there is a white bar containing logos for HOPE, Stanford Medicine, Genome Technology Center, and CFS Research Center, along with a 'Learn More' button.

Community Symposium
on the
MOLECULAR BASIS OF ME/CFS
STANFORD UNIVERSITY, PALO ALTO, CALIFORNIA
Saturday, August 12, 2017

HOPE | **Stanford** MEDICINE | Genome Technology Center | cfs research center

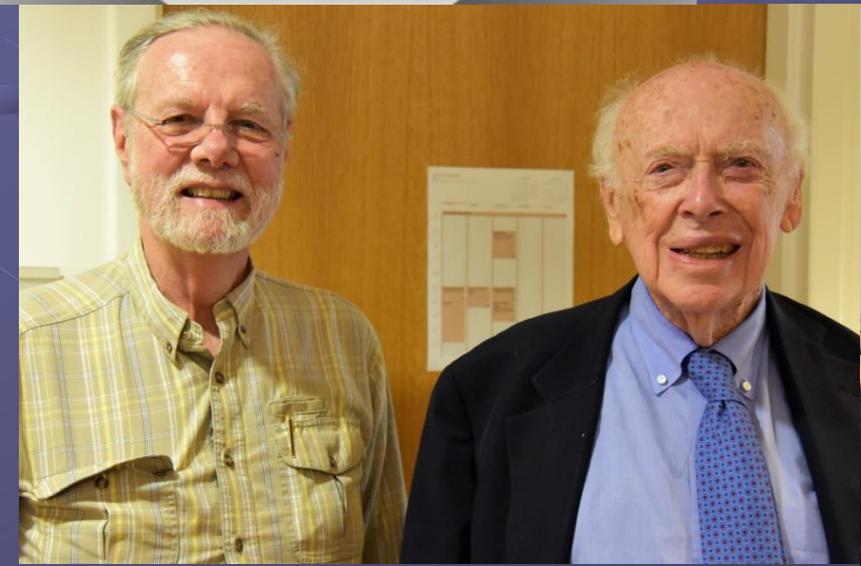
Learn More

~300 attendees; ~3000 live-stream participants
Available on OMF YouTube & DVD

www.omf.ngo/community-symposium/



Team OMF in action





www.omf.ngo/community-symposium/

RESEARCH UPDATE

HOPE



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THE END
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H O P E

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**THE END
ME/CFS
PROJECT**

Severely ill Big Data Study

Metabolomics Validation & Genomics Study

Innovative, cost-effective Technologies from Stanford

Next Steps: Launching a new Molecular Study

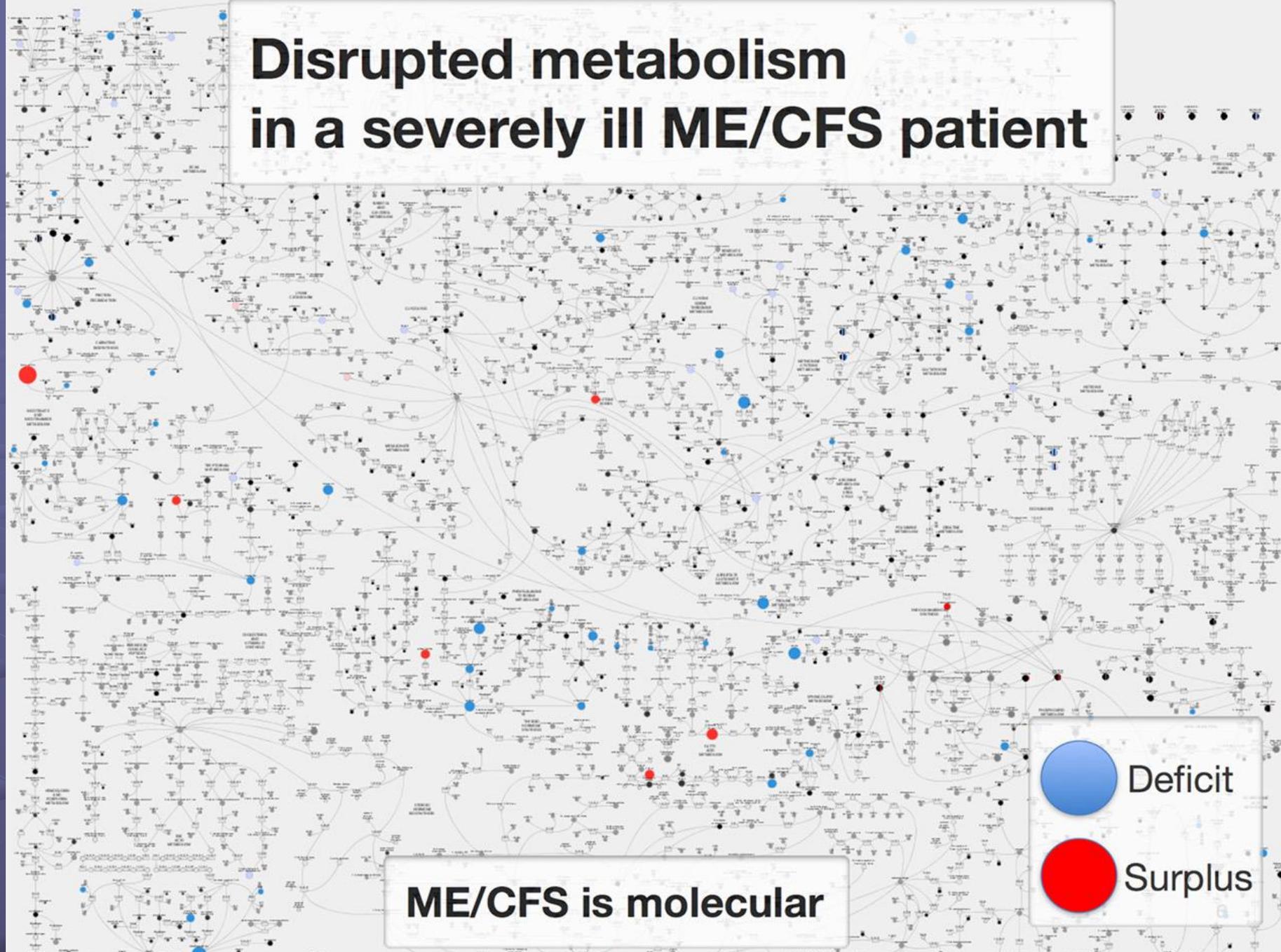
Severely ill ME/CFS Big Data Study Status

- **Goal:** Identify molecular signals, biomarkers, defects
- **Methods:** Profiling of DNA, RNA, proteins, metabolites & microbiome; clinical tests
- **Results:** Evidence of metabolic defects observed; analysis still underway.
- **What's next:** Continue analysis; share results openly as resource for research & clinical communities

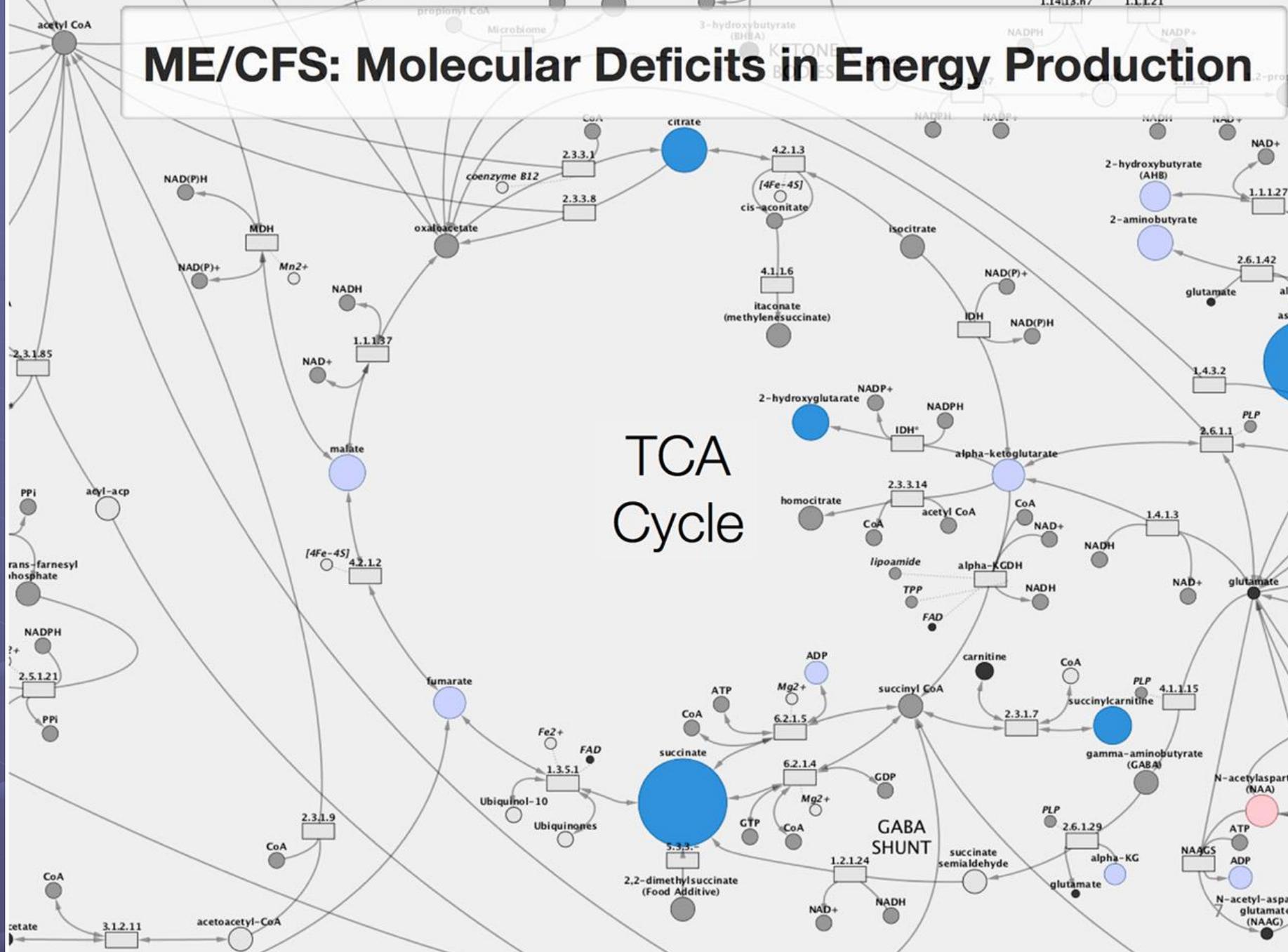
What is Metabolomics?

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

Disrupted metabolism in a severely ill ME/CFS patient



ME/CFS: Molecular Deficits in Energy Production



Robert Naviaux, MD, PhD, March 2017:Cell Danger Response

“I believe that at the root of ME/CFS is a treatable metabolic syndrome. If cell signals can be changed by new therapy, then healing and recovery might be possible.” (Suramin?)

Neil McGregor, Chris Armstrong, Melbourne Australia:

ME/CFS a heterogenous syndrome: Metabolomics and genotyping

Maureen Hanson, Cornell University:

Disturbances in Fatty Acid & Lipid Metabolism

Additional recent research findings

Mark Davis (Stanford Immunology):

ME/CFS could be an autoimmune disease:

Patient T cells show clonal expansion, seen in infection & autoimmunity

Next step: What are these T cells targeting?

Jonas Bergquist (Uppsala) & Alan Light (University of Utah):

Measuring autoantibodies in plasma and spinal fluid

- **Cytokines:** Some increased, some decreased
 - Certain cytokines correlate with disease severity, indicate ME/CFS is an inflammatory disease (1)
- **Plasma immune signatures:** Showing immunological dysfunction (2)
- **Elevated auto-antibodies (4)**
- **Reduced Natural Killer cell cytotoxicity – (5)**

- **Possible environmental triggers:** viruses (EBV), pathogens (11)(12), injury, surgery, others...
- **Rituximab:** Benefit from B-lymphocyte depletion using the anti-CD20 antibody rituximab (13) (14)
- **Clinical tests:** Results usually normal

- **Microbiome**: Reduced diversity & altered composition of gut microbiome (8)

- **Genetics**:

- Suspicious genetic mutations identified; heterogeneity could explain diverse symptoms

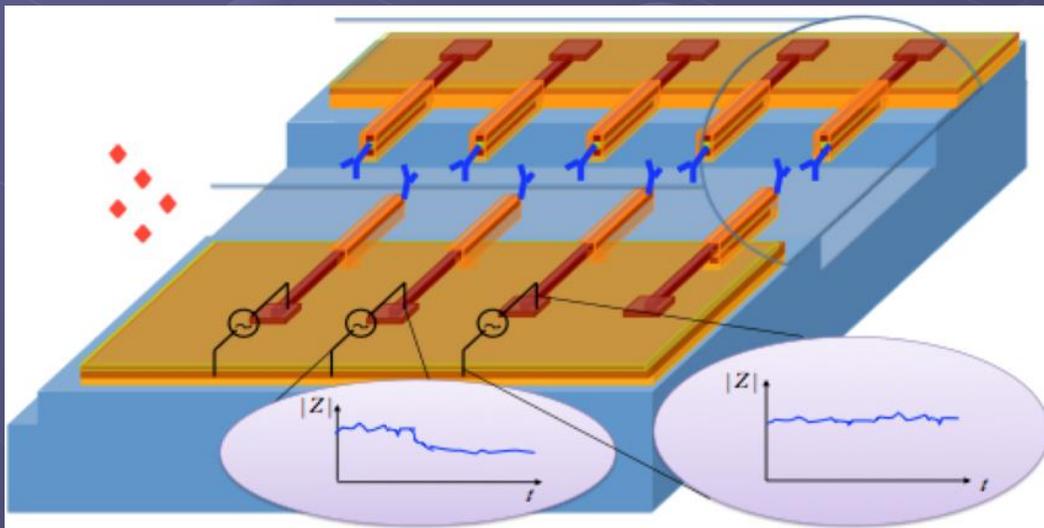
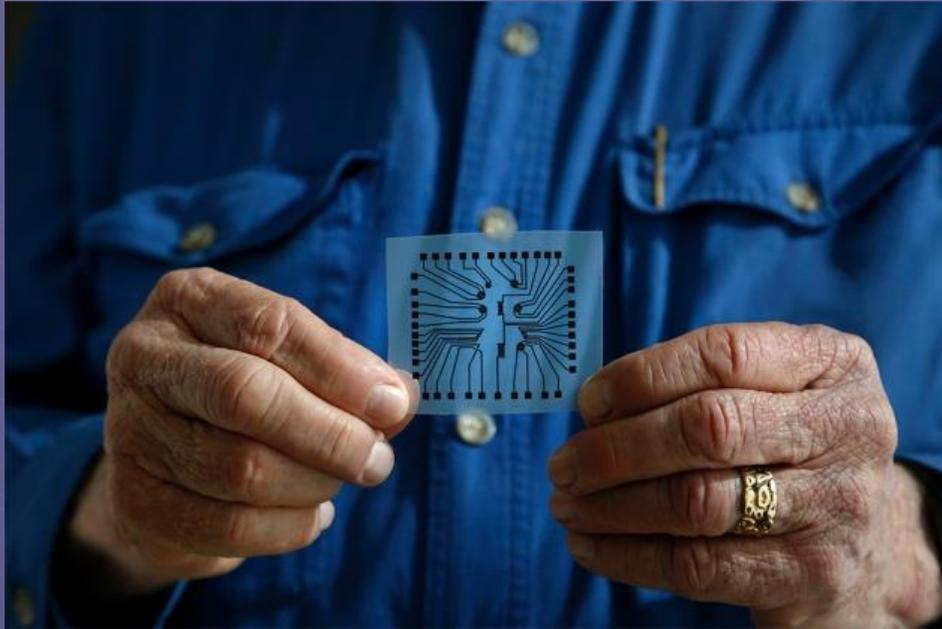
- Abnormal gene expression after exercise (9)

- Evidence for a possible heritable predisposition (10)

Next ME/CFS Research Projects Funded by OMF: A Molecular Approach

- Multi-omics profiling of families to further define molecular basis of ME/CFS (Ron Davis)
- **Metabolomics validation study, integration with genomics (Naviaux/Davis)**
- Immunology study with single-cell technologies (Ron Davis & Mark Davis)
- **Developing blood diagnostic & drug-screening platform (Davis)**

Inexpensive Disruptive Technologies from Stanford

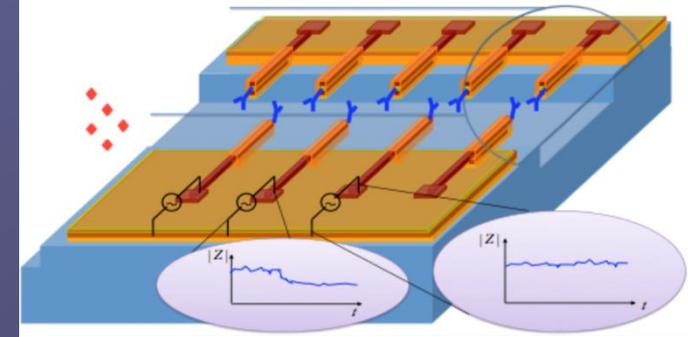


Nanoneedle biosensors to detect cells, molecules of interest via electrical signals



Stanford
MEDICINE

Genome Technology Center



Towards a blood diagnostic for ME/CFS

- ME/CFS cells stressed with salt react very differently than healthy cells in nanoneedle biosensors
- **Healthy plasma + ME/CFS patient cells reacts like healthy**
- ME/CFS plasma + healthy cells reacts in between



Stanford
MEDICINE

Genome Technology Center

Towards high-throughput, cost-effective drug screening for ME/CFS

- Lab-on-a-chip platform can be produced on 2D
Printer for < 1 cent (Esfandyarpour et al., PNAS 2017)
- Working on screening potential treatments in
chip platforms, including FDA-approved drugs

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.

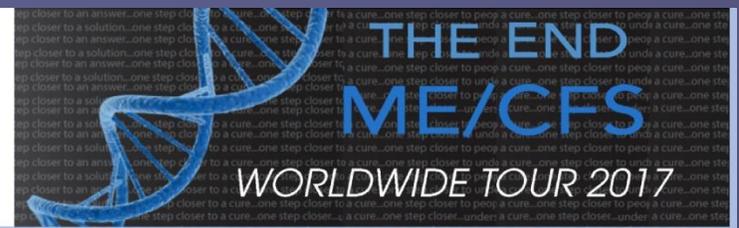
**Now we need to step this up
to find a cure.**

With significant funding, we can do this.

What can YOU do?

- Join a community
- Join forums & blogs
- Fundraise for research
- Take care of a loved one
- Sign up for our e-newsletter
- “Like” us on Facebook
- Follow us on Twitter

Get Involved!



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 brings together individuals working together to end ME/CFS.

WWW.OMF.NGO

It's Time to Move Forward Together



Join Team OMF to Find Answers!



Open Medicine Foundation

www.omf.ngo - linda@omf.ngo

Resources (upon request)

- (1) PNAS: Mark Davis et al, Stanford Univ, 2017
- (2) ScienceAdvances: Lipkin et al, Columbia Univ, 2015
- (3) Translational Psychiatry: Lipkin et al, Columbia Univ, 2017
- (4) Brain, Behavior, and Immunity: Scheibenbogen et al, Charité, Berlin, 2016
- (5) Clinical & Experimental Immunology: Marshall-Gradisnik, Griffith Univ, Australia, 2016
- (6) PNAS: Naviaux et al, Univ of California-San Diego, 2016
- (7) Molecular Biosystems: Hanson et al, Cornell Univ, 2017
- (8) Microbiome: Hanson et al, Cornell Univ, 2016
- (9) Journal of Internal Medicine: Light et al, Univ of Utah, 2012
- (10) BMC Neurology: Light et al, Univ of Utah, 2011
- (11) BMJ: “Dubbo Study”, Hickie et al, Australia, 2006
- (12) BMC Gastroenterology: Morch et al, Norway, 2013
- (13) Plos One: Fluge et al, Univ of Bergen, Norway, 2011
- (14) Plos One: Fluge et al, Univ of Bergen, Norway, 2015