



Solve ME/CFS Initiative

Leveraging patient-centered
research to cure ME/CFS

Our Mission: Make ME/CFS understood, diagnosable and treatable |
www.SolveCFS.org

The Solve ME/CFS Initiative

Our Mission: Make ME/CFS understood, diagnosable and treatable | www.SolveCFS.org

- Longest-standing ME/CFS organization in the US
- Funded ME/CFS research
- Built the SolveCFS BioBank for use by any qualified ME/CFS researcher.



Our Mission: Make ME/CFS understood, diagnosable and treatable
| www.SolveCFS.org

My comments today...

- What does the IOM report change?
- For those new to the disease, background
- Why does this disease matter to all of us, not just patients?
- At what levels has NIH funded ME/CFS research?
- **WHAT NOW?**



Our Mission: Make ME/CFS understood, diagnosable and treatable
| www.SolveCFS.org

What changed when the IOM report was published?

- Federal government affirmed that ME/CFS is a serious, debilitating, physical disease.



What changed when the IOM report was published?

- Federal government affirmed that ME/CFS is a serious, debilitating, physical disease.
- **No credible barriers now to increased research funding.**



What didn't change with the publication of the IOM report?

- Still a complex, multi-system disease in the early stages of medical research and understanding
- Patients continue to suffer



For those new to understanding the disease...

- 1) Most people have not believed it is “real”



For those new to understanding the disease...

- 1) Most people have not believed it is “real”
- 2) **The disease name (Chronic Fatigue Syndrome) has been an impediment**



For those new to understanding the disease...

- 1) Most people have not believed it is “real”
- 2) The disease name (Chronic Fatigue Syndrome) has been an impediment
- 3) **Because the disease is complex, it has been poorly defined, making it difficult to diagnose**



For those new to understanding the disease...

- 1) Most people have not believed it is “real”
- 2) The disease name (Chronic Fatigue Syndrome) has been an impediment
- 3) Has been poorly defined, making it difficult to diagnose
- 4) **Has been erroneously described as a primarily psychological disease**



For those new to understanding the disease...

- 1) Most people have not believed it is “real”
- 2) The disease name (Chronic Fatigue Syndrome) has been an impediment
- 3) Has been poorly defined, making it difficult to diagnose
- 4) Has been erroneously described as a primarily psychological disease
- 5) **Many medical professionals know little, so patients often don't get medical care.**



Why should this illness matter to everyone, not just patients and their loved ones?

- \$17 - \$24 billion economic burden on our nation
- There are so many who suffer:
 - IOM report – 836,000 to 2,500,000 Americans
 - CDC figure – 1,000,000 Americans



2014 NIH funding and prevalence for selected diseases

Disease	funding (millions)	# of Americans	\$'s spent per patient
HIV/AIDS	\$ 2,978	1,200,000	\$ 2,482
Lupus	\$ 99	350,000	\$ 283
Multiple sclerosis	\$ 102	400,000	\$ 255
Autism	\$ 188	3,500,000	\$ 54
ME/CFS	\$ 5	1,000,000	\$ 5

Source: U.S. Institutes of Health. "Estimates of Funding for Various Research. Condition and Disease Categories (RCDC). NIH, published March 7, 2014. http://report.nih.gov/categorical_spending.aspx



Our Mission: Make ME/CFS understood, diagnosable and treatable |
www.SolveCFS.org

How does ME/CFS rank out of the 242 NIH 2014 spending categories?

	Research/Disease Areas (Dollars in millions and rounded)	FY 2014Actual
1	Clinical Research	\$11,087
2	Genetics	\$7,324
3	Prevention	\$6,858
4	Biotechnology	\$5,889
6	Neurosciences	\$5,580
7	Cancer	\$5,392
8	Infectious Diseases	\$5,002
9	Women's Health 5/	\$3,935
10	Brain Disorders	\$3,894
11	Behavioral and Social Science	\$3,688
12	Rare Diseases	\$3,639
13	Pediatric	\$3,486
14	Bioengineering	\$3,329
15	Clinical Trials	\$3,221
16	HIV/AIDS 6/	\$2,978
17	Health Disparities 5/	\$2,734
18	Human Genome	\$2,701
19	Aging	\$2,556



How does ME/CFS rank out of the 242 NIH 2014 spending categories?

20	Minority Health 5/	\$2,514
21	Mental Health	\$2,213
22	Cardiovascular	\$1,950
23	Emerging Infectious Diseases	\$1,930
24	Biodefense 1/	\$1,746
25	Neurodegenerative	\$1,743
26	Digestive Diseases	\$1,607
27	Immunization	\$1,607
28	Vaccine Related	\$1,573
29	Substance Abuse 9/	\$1,564
30	Nutrition	\$1,555
31	Stem Cell Research	\$1,391
32	Health Services	\$1,342
33	Lung	\$1,329
34	Basic Behavioral and Social Science	\$1,234
35	Heart Disease	\$1,224
36	Hematology	\$1,189
37	Diagnostic Radiology	\$1,078
38	Drug Abuse (NIDA Only) 3/	\$1,018
39	Diabetes 2/	\$1,011



How does ME/CFS rank out of the 242 NIH 2014 spending categories?

40	Patient Safety	\$1,008
41	Obesity	\$857
42	Regenerative Medicine	\$836
43	Eye Disease And Disorders Of Vision	\$824
44	Autoimmune Disease	\$822
45	Orphan Drug	\$809
46	Dementia	\$704
47	Breast Cancer	\$682
48	Stem Cell Research - Nonembryonic - Non-Human	\$627
49	Networking and Information Technology R&D 8/	\$612
50	Comparative Effectiveness Research	\$610
51	Liver Disease	\$605
52	Alzheimer's Disease	\$562
53	Transplantation	\$561
54	Kidney Disease	\$549
55	Perinatal Period - Conditions Originating in Perinatal Period	\$534
56	Vaccine related (AIDS) 6/	\$533
57	Pain Research	\$499
58	Rehabilitation	\$494
59	Urologic Diseases	\$494



How does ME/CFS rank out of the 242 NIH 2014 spending categories?

Skip categories ranked 60 - 99



How does ME/CFS rank out of the 242 NIH 2014 spending categories?

100	Hypertension	\$216
101	Injury - Trauma - (Head and Spine)	\$216
102	Mind and Body	\$211
103	Perinatal - Birth - Preterm (LBW)	\$206
104	Estrogen	\$203
105	Rural Health	\$197
106	Autism	\$188
107	Conditions Affecting the Embryonic and Fetal Periods 11/	\$175
108	Malaria	\$169
109	American Indians / Alaska Natives	\$166
110	Pediatric AIDS 6/	\$166
111	Stem Cell Research - Embryonic - Human	\$166
112	Neuropathy	\$156
113	Epilepsy	\$154
114	Stem Cell Research - Embryonic - Non-Human	\$150
115	Organ Transplantation	\$142



How does ME/CFS rank out of the 242 NIH 2014 spending categories?

Skip categories ranked 116 to 180



How does ME/CFS rank out of the 242 NIH 2014 spending categories?

181	Stem Cell Research - Umbilical Cord Blood/ Placenta - Human	\$28
182	Emphysema	\$27
183	Gene Therapy Clinical Trials	\$26
184	Aphasia	\$24
185	Headaches	\$24
186	Scleroderma	\$24
187	Small Pox	\$24
188	Tuberous Sclerosis	\$24
189	Lyme Disease	\$23
190	Injury - Unintentional Childhood Injury	\$22
191	Suicide Prevention	\$22
192	Cerebral Palsy	\$21
193	Neurofibromatosis	\$21
194	Migraines	\$20
195	Sudden Infant Death Syndrome	\$20
196	Usher Syndrome	\$19



How does ME/CFS rank out of the 242
NIH 2014 spending categories?

Skip 197 to 229



How does ME/CFS rank out of the 242 NIH 2014 spending categories?

230	Mucopolysaccharidoses (MPS)	\$6
231	Batten Disease	\$5
232	Chronic Fatigue Syndrome (ME/CFS)	\$5
233	Hydrocephalus	\$5
234	Global Warming Climate Change	\$4
235	Pick's Disease	\$4
236	Tourette Syndrome	\$4
237	Hepatitis - A	\$3
238	Valley Fever	\$3
239	Vulvodynia	\$3
240	Hyperbaric Oxygen	\$2
241	Pelvic Inflammatory Disease	\$2
242	Diethylstilbestrol (DES)	\$1



This 2014 spending is not an anomaly.

- NIH ME/CFS funding has averaged roughly \$5.5 million in the fourteen years between 1999 and 2013.
- In the period 1987 to 2012, spending on ME/CFS decreased by 27% while total NIH funding more than doubled.



Understanding the economic burden on
our nation, the suffering of our citizens,
and disease validation with the IOM
report...

What now?



What now?

1. Biomedical research and studies **funded in proportion** to others with a similar disease burden - **\$250 million per year**

2014 NIH funding and prevalence for selected diseases			
Disease	funding (millions)	# of Americans	\$'s spent per patient
HIV/AIDS	\$ 2,978	1,200,000	\$ 2,482
Lupus	\$ 99	350,000	\$ 283
Multiple sclerosis	\$ 102	400,000	\$ 255
Autism	\$ 188	3,500,000	\$ 54
ME/CFS	\$ 5	1,000,000	\$ 5



What now?

- 1) Biomedical research and studies funded in proportion to others with similar disease burden - **\$250 million per year**
- 2) **Resolve organizational and institutional barriers within the federal government (e.g. move ME/CFS out of the Office of Research on Women's Health)**



What now?

- 1) Biomedical research and studies funded in proportion to others with similar disease burden - \$250 million per year
- 2) Resolve organizational and institutional barriers within the federal government (e.g. move ME/CFS out of the Office of Research on Women's Health)
- 3) **Accelerate education of our nation's medical professionals.**





Solve ME/CFS Initiative

Leveraging patient-centered
research to cure ME/CFS

From the IOM report...

“Knowing is not enough; we must apply.
Willing is not enough; we must do.”

--Goethe

