

Investment in research saves lives and money



facts about:

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex chronic disease with an array of debilitating symptoms, including extreme exhaustion, unrefreshing sleep, problems with concentration and short-term memory, joint pain, tender lymph nodes, sore throat, and headache. The cause of ME/CFS is unknown, and there is no existing cure for the condition.

"If you think research is expensive, try disease."

- Mary Lasker 1901-1994

The Cost:

- ME/CFS costs the U.S. up to \$24 billion each year in direct medical costs and lost productivity.*
- Up to 69% of those with ME/CFS are unemployed, with at least 25% becoming house-bound from their illness.*
- Many with ME/CFS have comorbid disorders such as irritable bowel syndrome, dysautonomia, and fibromyalgia, which further contribute to the physical and economic burden of the disease.*

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Today:

- Up to 2.5 million Americans are estimated to have ME/CFS.*
- Up to 91% of those with ME/CFS have not been diagnosed.*
- As many as four times more women have ME/CFS than men.*
- The average age of onset of ME/CFS is 33, but people of all ages can develop ME/CFS; this disease has been reported in patients younger than 10 and older than 80.**

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†SOLVE ME/CFS INITIATIVE <WWW.SOLVECFS.ORG>

IMPROVING LIVES
SAVING MONEY

HOW RESEARCH IMPROVES LIVES:

- A computational study took genetic markers previously found to correlate with ME/CFS and created a mathematical model to predict genetic risk of ME/CFS with 80% accuracy. Future research can improve upon this approach to identify individuals at a high risk of developing ME/CFS.**
- Investigators at the Centers for Disease Control and Prevention (CDC) found genetic associations between ME/CFS and gene variants in immune response and inflammation-related genes. Future research is needed to validate these genetic associations to improve both diagnostic tests and treatment development.[§]

HOW RESEARCH CAN SAVE MONEY:

- A small study found that rituximab, an FDA-approved treatment used for lymphoma, induced relapse of ME/CFS symptoms in some patients. While further studies are needed, findings suggest positive outcomes with this therapeutic intervention. The U.S. could save nearly \$24 billion if all ME/CFS patients were able to return to their pre-illness level of productivity.¶¶^
- If a cure for ME/CFS were to be found, the U.S. would save \$8,675 per patient annually in direct medical costs. ¶^

‡ BHATTACHARJEE, M. ET AL. HUMAN GENOMICS. 2015; 9:8
§ RAJEEVAN, M. ET AL. HUM IMMUNOL. 2015; 76(8):553-560
¶ FLUGE, O. ET AL. PLoS ONE. 2011; 6(10)

¶¶ INSTITUTE OF MEDICINE
<IOM.NATIONALACADEMIES.ORG>
^ JASON, L.A. ET AL. DYNAMIC MEDICINE. 2008; 7(6)

survivor:

NAME: Walt Irvine

AGE: 59

CONDITION: ME/CFS



For Walt Irvine, ME/CFS has wreaked havoc on his health, career, and family. Before Walt was diagnosed with ME/CFS in 2012, he was a computer programmer and the primary caretaker of his late wife, Char, who also suffered from ME/CFS for nearly 20 years. However, when Walt developed ME/CFS, he found he was unable to provide for his family. When Walt's symptoms were most severe, it was impossible for him to care for himself; he was unable to cook, clean, and even shower. He eventually went on disability and became home-bound.

Like so many others with ME/CFS, Walt and Char faced skepticism and stigma when they sought help. Tragically, this lack of acceptance and support, coupled with little hope for a cure, drove Char to take her own life in February 2015.

Despite the loss of his wife, Walt presses on. His determination to not give up has led to his involvement in "ME Act Up," an advocacy group focused on bringing those who are affected by ME/CFS together. His step-daughter, Kaycee, is honoring her mother's death by running in races across Colorado and raising funds for the Solve ME/CFS Initiative. Walt participates in clinical trials whenever possible and wants more to be done to uncover the causes of ME/CFS. He believes ME/CFS research "desperately needs funding on the federal level," and will continue working to increase awareness and support for all those suffering from this devastating disease.

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Hope for the Future:

- ❑ The Chronic Fatigue Syndrome Advisory Committee at the U.S. Department of Health and Human Services has made several recommendations to improve ME/CFS research and work towards better treatments and potential cures. Included in their recommendations: search for biomarkers via a clinical study at the NIH Clinical Center, advance treatments and therapeutics, and provide research funding that better reflects the burden of disease, which would be approximately \$250 million per year, compared to the current level of approximately \$5.4 million per year.*†
- ❑ New research suggests that two consecutive exercise tests may simplify ME/CFS diagnosis, in which post-exertional malaise (PEM) is a hallmark symptom. The second exercise test helps to identify patients who lack a typical exercise recovery response, and could be a straightforward solution to improving accurate ME/CFS diagnosis.‡
- ❑ A National Institutes of Health (NIH) funded study has identified a potential biomarker for ME/CFS. Early in the course of the disease, patients with ME/CFS show altered inflammatory blood markers, which could help doctors more accurately diagnose and treat ME/CFS in the future.§

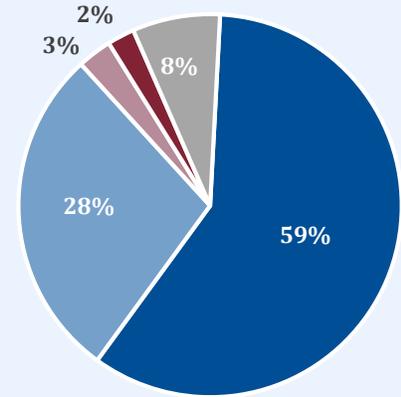
* NATIONAL INSTITUTES OF HEALTH <WWW.NIH.GOV>
† GREEN C.R. ET AL. ANN INTERN MED. 2015; 162:860-865.

‡ SNELL, C.R. ET AL. PHYS THER. 2013; 93(11):1484-92.
§ HORNIG, M. ET AL. SCIENCE ADVANCES. 2015; E1400121

National Poll: Candidates Should Have a Basic Understanding of Science

How important do you think it is that candidates for President and Congress have a basic understanding of the science informing public policy issues?

A RESEARCH!AMERICA AND SCIENCE DEBATE POLL OF U.S. ADULTS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN SEPTEMBER 2015.

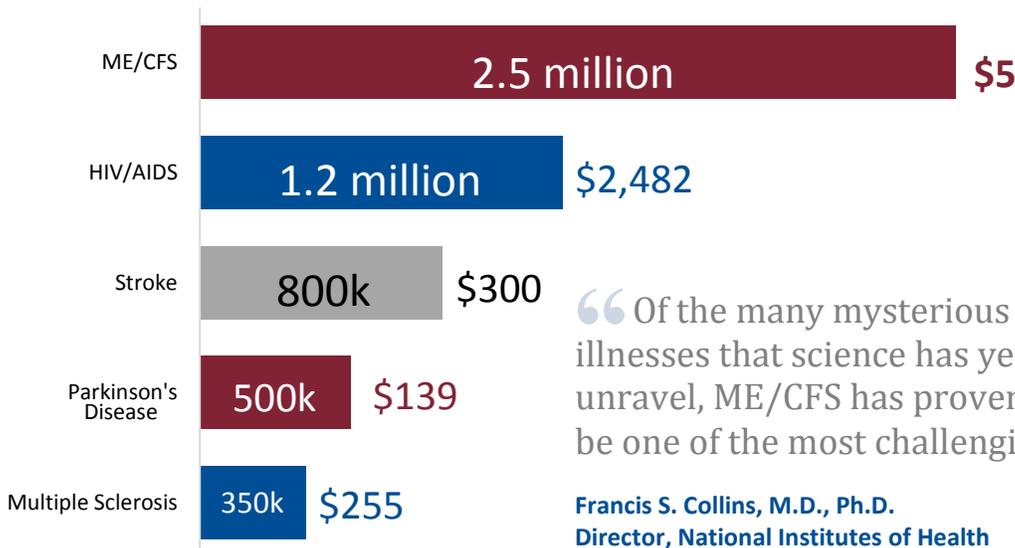


- Very Important
- Somewhat Important
- Not Very Important
- Not Important At All
- Not Sure

The Bottom Line:

ME/CFS is a life-changing illness for 2.5 million Americans. The cause of ME/CFS remains unknown, and there is no cure. Current treatments seek only to alleviate some of the symptoms. Given the dire circumstances ME/CFS patients and their families face, greater investment in ME/CFS research is needed now to prevent, diagnose, treat, and cure this disease.

Disease Prevalence in U.S. and Research Funding per Person Affected



“Of the many mysterious illnesses that science has yet to unravel, ME/CFS has proven to be one of the most challenging.”

Francis S. Collins, M.D., Ph.D.
Director, National Institutes of Health

“People don't really understand how it can destroy someone's life. It's not fatigue. It's far, far worse than most people can even imagine.”

Laura Hillenbrand, best-selling author of *Seabiscuit: An American Legend* who has suffered from ME/CFS since 1987

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