

Investment in research saves lives and money



facts about:

Chronic Fatigue Syndrome

*"If you think research is expensive, try disease."
— Mary Lasker 1901–1994*

Chronic fatigue syndrome (CFS) is a complex illness with an array of debilitating symptoms, including extreme fatigue, problems with concentration and short-term memory, joint pain, tender lymph nodes, sore throat and headache. The cause of CFS is unknown.

Today:

- More than 1 million Americans have chronic fatigue syndrome.
- More than 80% of Americans with CFS have not been diagnosed.
- Four times more women have CFS than men.
- CFS is most common in Americans ages 40 to 59, but people of all ages can develop CFS.

SOURCE: CENTERS FOR DISEASE CONTROL AND PREVENTION (WWW.CDC.GOV)
THE CFIDS ASSOCIATION OF AMERICA (WWW.CFIDS.ORG)

The Cost:

- Chronic fatigue syndrome costs the U.S. as much as \$25 billion each year in medical costs and lost productivity.*
- A quarter of Americans with CFS must stop work because of their illness.**

SOURCE: *JASON, L. ET AL. INTERNATIONAL ASSOCIATION FOR CHRONIC FATIGUE SYNDROME, 8TH INTERNATIONAL IACFS CONFERENCE, JANUARY 12-14, 2007.

**REYNOLDS, K.J. ET AL. COST EFFECTIVENESS AND RESOURCE ALLOCATION. 2004; 2:4.

survivor



NAME: PATRICK VENETUCCI

AGE: 38

CONDITION: CHRONIC FATIGUE SYNDROME

Patrick Venetucci of Chicago, Illinois, was suddenly struck with chronic fatigue syndrome (CFS) on May 13, 1999, while living and working in Japan. One minute he felt normal and the next his vision changed, he felt dizzy and nauseous, and he began having cognitive difficulties. His muscles vibrated uncontrollably, and he became so profoundly weak that he was bedridden for months. Patrick visited 25 doctors, including some of the best in the U.S., seeking diagnosis and treatment. By eliminating all other explanations, Patrick was diagnosed with CFS.

Before his illness, Patrick was an international business executive, a black-belt in karate and an avid mountain climber. Today, he is on a different career path and an afternoon at the zoo with his kids can lead to a relapse. Patrick describes CFS as a "brain problem triggered by physical activity." Patrick emphasizes that CFS is "not just about fatigue. It's much harder to push through the constant nausea and dizziness and the difficulty processing sights, sounds and information."

Patrick's only current treatment is a medication to raise his low blood pressure, a condition that occurs in some CFS patients. He is determined to see more CFS research funded and regularly attends research updates presented by Leonard Jason, PhD, a leading CFS researcher at DePaul University who is funded in part by the NIH. Patrick wants researchers to find a biomarker for CFS. "Without a biomarker we can't truly identify who has the disease or find a target for a cure."

SAVING LIVES SAVING MONEY

HOW RESEARCH SAVES LIVES:

- Research has shown that many patients with CFS experience symptoms when sitting or standing because of changes in blood pressure or pulse. Treatments to enhance blood flow can improve symptoms.*
- A study funded by the Agency for Healthcare Research and Quality shows that cognitive behavior therapy, rehabilitation and exercise therapy are associated with restoring CFS patients' ability to work.**
- CDC scientists led a study that revealed a genetic basis for CFS. Researchers are using these findings to develop diagnostics and treatments for CFS.***

SOURCE: *ROWE, P.C. AND LUCAS, K.E. AMERICAN JOURNAL OF MEDICINE. 2007; 120:E13.

**ROSS, S.D. ET AL. ARCHIVES OF INTERNAL MEDICINE. 2004; 164:1098-1107.

***VERNON, S.D. AND REEVES, W.C. PHARMACOGENOMICS. 2006; 7(3):345-354.

HOW RESEARCH SAVES MONEY:

- The longer CFS goes undiagnosed, the more complicated the course of illness. Better methods of detecting and diagnosing CFS could reduce medical expenses and suffering.*
- The U.S. could save an average of \$20,000 per person annually when researchers find a treatment or cure for CFS that returns patients to their pre-illness level of productivity. **

SOURCE: *NISENBAUM R. ET AL. HEALTH QUALITY OF LIFE OUTCOMES. 2003; 1(1): 49.

**REYNOLDS, K.J. ET AL. COST EFFECTIVENESS AND RESOURCE ALLOCATION. 2004; 2:4.

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Hope for the Future:

- A small group of CFS patients experienced significant improvements from taking the antiviral drug, valganciclovir. Larger clinical trials are under way to test its effectiveness in patients who had a flu-like illness at the onset of CFS.*
- Several NIH institutes, led by the Office of Research on Women's Health, are funding studies to determine if a specific set of proteins in spinal fluid can be used as a biomarker, to explain how antidepressants can relieve symptoms and to examine the roles of the nervous and immune systems in CFS.**
- Through advances in imaging technology, researchers can see structural and chemical differences in the brains of CFS patients, providing a better understanding of the disease.***

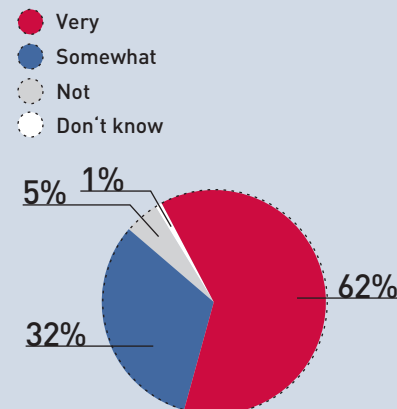
SOURCE: *KOGELNIK, A.M. ET AL. JOURNAL OF CLINICAL VIROLOGY. 2006; 37 SUPPL. 1:S33-S38.

**NATIONAL INSTITUTES OF HEALTH (WWW.NIH.GOV)

***THE CFIDS CHRONICLE. 2007; 9.

Research Investment Important to Health Care

How important do you think it is that we invest in more research to assure that there is a solid scientific base for health care?



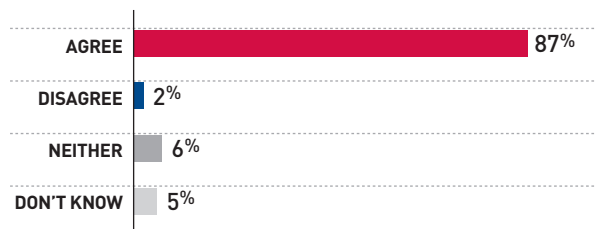
SOURCE: TAKING OUR PULSE: THE PARADE/RESEARCH!AMERICA HEALTH POLL CHARLTON RESEARCH COMPANY, 2006

PHYSICIAN SURVEY

SOURCE: 2006 DOCSTYLES SURVEY, CDC

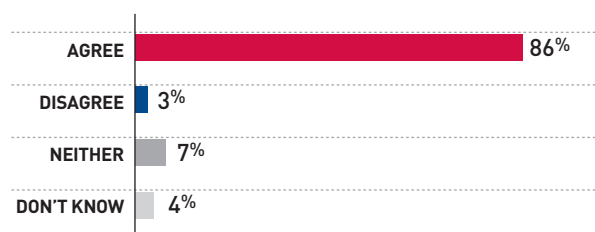
CFS can impair quality of life

Physicians agree that chronic fatigue syndrome impairs the quality of life in patients.



CFS can impair quality of life for caregivers

Physicians also agree that the quality of life is impaired for caregivers of chronic fatigue syndrome patients.



The Bottom Line:

Chronic fatigue syndrome is a life-changing illness for more than 1 million Americans. The cause of CFS remains unknown, and current treatments only alleviate some of the symptoms. Greater investment in research is needed now to prevent, treat and cure chronic fatigue syndrome.

“CFS is to fatigue what a nuclear bomb is to a match. It is an absurd mischaracterization.”

Laura Hillenbrand is the best-selling author of *Seabiscuit: An American Legend* and has suffered from CFS since 1987.

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For additional information, contact

the Centers for Disease Control and Prevention at www.cdc.gov/cfs
OR The CFIDS Association of America at 704.365.2343 or www.cfids.org/cfs.

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