

# Investment in research saves lives and money



facts about:

## Multiple Sclerosis (MS)

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

*- Mary Lasker 1901-1994*

### What is MS?

MS is a chronic, unpredictable disease involving immune system attacks against the central nervous system, or CNS, which includes the brain, spinal cord and optic nerves. MS damages myelin, the protective insulation surrounding nerve fibers. This damage interferes with neural communication within the CNS, producing a variety of symptoms including blurred vision, walking difficulties, numbness, fatigue, spasticity, bladder and bowel disturbances, pain, cognitive deficits, and other symptoms that may profoundly interfere with quality of life.\*

SOURCES: \* HUMPHRIES, C. NATURE. 2012;484(7393);S10.  
‡ KALB, R. "MULTIPLE SCLEROSIS: A GUIDE FOR FAMILIES." 2005.  
‡‡ SELLNER, J. ET AL. AUTOIMMUNITY REVIEWS. 2011;10(8);495:502.  
‡‡‡ NATIONAL MS SOCIETY {WWW.NATIONALMSSOCIETY.ORG}  
‡‡‡ HUMPHRIES, C. NATURE. 2012;484(7393);S10.

### Today:

- ❑ MS is typically diagnosed in young adulthood when decisions are being made about marriage, children and careers.‡
- ❑ Women are increasingly more likely than men to develop MS.‡‡
- ❑ There is no MS surveillance program, making it difficult to quantify the rising incidence. It's estimated that more than 2.1 million people worldwide have MS, including 400,000 Americans.‡‡‡
- ❑ Current therapies partially reduce attacks and slow disease progression in relapsing forms of MS.‡‡‡
- ❑ There are no FDA-approved therapies for progressive forms of MS. Research is crucial to address this large unmet need.‡‡‡
- ❑ At disease onset, approximately 85% of patients have a relapsing form of MS. Relapses are unpredictable and can be several months apart but occur every two years on average.‡

SAVING LIVES  
SAVING MONEY

### HOW RESEARCH SAVES LIVES:

- ❑ MS has gone from an untreatable disease to one where there are now FDA-approved therapies that can impact the underlying disease process for the most common form of the disease.\*
- ❑ The drug interferon β-1b, developed through NIH-supported research, was shown to improve long-term and disability and extend lives in patients who received it during a clinical trial.\*\*
- ❑ Increased vitamin D levels and smoking avoidance have the potential to substantially reduce MS risk and influence disease progression. Improving our understanding of the environmental factors involved in MS can lead to new and more effective approaches to prevent this disease.\*\*\*

SOURCES: \* NATIONAL MS SOCIETY {WWW.NATIONALMSSOCIETY.ORG}  
\*\* GOODIN DS, ET AL. NEUROLOGY. 2012;78(17);1315-1322.  
\*\*\* ASCHERIO A, ET AL. NATURE REVIEWS NEUROLOGY. 2012; 8(11);602:12.

### HOW RESEARCH SAVES MONEY:

- ❑ Disease-modifying therapies can reduce the costs associated with MS.\*
- ❑ Health services research has indicated that management strategies leading to prevention of just one severe relapse can save \$12,870 per person by avoiding hospitalization or other medical care.\*\*
- ❑ Treatments that have the ability to stop MS before significant impairment has set in could save the U.S. up to an estimated \$20 billion annually.\*\*\*

SOURCES: \* NATIONAL MS SOCIETY, TEVA NEUROSCIENCE. "THE MULTIPLE SCLEROSIS TREND REPORT 2ND EDITION." 2010:20.  
\*\* BMC HEALTH SERVICES RESEARCH, "COST OF MANAGING AN EPISODE OF RELAPSE IN MULTIPLE SCLEROSIS IN THE UNITED STATES"  
\*\*\* NATIONAL MS SOCIETY {WWW.NATIONALMSSOCIETY.ORG}

### patient activist:



NAME: Carrie B. Scott  
AGE: 46  
CONDITION: Relapsing-Remitting MS  
Diagnosed at age 39

Carrie, a former marathon runner, aerobics and cycling instructor, and employee at a national insurance company is now much less active. She is unable to work because of disabling cognitive impairments from her MS. Originally manifesting as occasional hearing loss and intermittent knee pain, MS has become a daily burden and has sent Carrie to the ER four times in the past six months.

Receiving a diagnosis took multiple doctors and two years of evaluations - it was "a nightmare." Carrie has relocated (with her husband, three children, and three dogs) to be closer to caregivers and better medical treatment. On average, relapses confine Carrie to bed for six weeks, and the lingering effects are becoming more severe. Treatments for relapses are so harsh that she frequently avoids them. Carrie says "MS changed everything about me and it continues to consume me; it shakes my self-confidence and makes me question my worth as an individual. An invisible and incredibly lonely disease, I know there is no cure. It continues to take everything from me physically, emotionally and economically that I have worked for my entire life."

After every available treatment caused intolerable side effects worse than the disease, Carrie participated in a clinical trial for the drug Gilenya at Johns Hopkins University. It became the first FDA-approved oral therapeutic in 2010. Gilenya is the only tolerable treatment for Carrie, who had been enduring painful trial-and-error experimentation with other drugs for six years. Boosting our national investments in MS research is desperately needed to help patients like Carrie who are faced with this disabling disease.

# facts about: } Multiple Sclerosis

## The Cost:

- ❑ **PER PERSON:** \$69,000 annually and increasing\*
- ❑ **ANNUAL ATTACKS:** Annual costs \$9,789 higher than non-relapsing patients for patients experiencing at least one attack a year.\*\*
- ❑ **EMPLOYMENT LOSS:** Only 30% or less of previously employed MS patients are working 10 to 15 years after receiving a diagnosis of MS.\*\*\*

SOURCES: \*NATIONAL MS SOCIETY (WWW.NATIONALMSSOCIETY.ORG)  
\*\*OLEEN-BURKEY M, ET AL. PATIENT. 2012; 5(1),57-69.  
\*\*\*RUMRILL, PD, ET AL. "EMPLOYMENT ISSUES AND MULTIPLE SCLEROSIS." 2008;19-38.

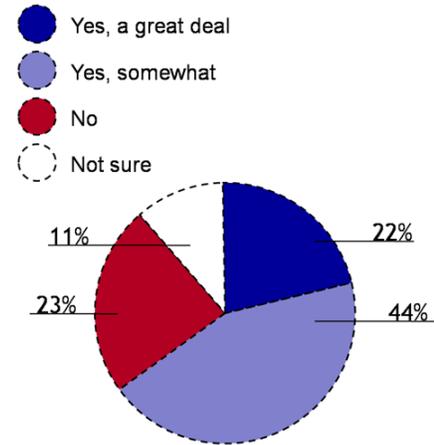
## Hope for the Future:

- ❑ **STOPPING MS:** The newly formed International Progressive MS Collaborative has identified key research priorities to stop MS progression. This is the largest effort to date aimed at speeding research on progressive MS and includes the MS Societies of Canada, Italy, the Netherlands, the UK and the US, and the MS International Federation. It offers hope for addressing the unmet need for treatments for people living with deadly, progressive MS.\*
- ❑ **RESTORING FUNCTION:** New studies into the potential of stem cells, including adult skin cells, as a source of nervous system repair, and research to discover new targets to stimulate natural myelin repair processes, are driving progress toward reversing the damage caused by MS. Innovative rehabilitation and exercise programs aimed at improving mobility, fatigue and cognitive problems, and new attention to the need for research to treat hard-to-manage symptoms such as spasticity, pain and tremor, offer hope for improving quality of life for people living with MS worldwide.\*\*
- ❑ **ENDING MS:** The International MS Genetics Consortium, launched with funding from the National MS Society and supported by the NIH and other funders, is nearing the end of a nine year effort to establish a comprehensive atlas of common genetic variations that affect susceptibility to MS and to identify novel disease candidate genes, pathways and networks. Its members have established an open data platform to facilitate research by all qualified investigators.\*\*\*

SOURCES: \*FOX, RJ, ET AL. MULTIPLE SCLEROSIS. 2012;18(11);1534-1540.  
\*\*NATIONAL MS SOCIETY (WWW.NATIONALMSSOCIETY.ORG)  
\*\*\*HARVARD NEURODISCOVERY CENTER  
(WWW.NEURODISCOVERY.HARVARD.EDU/RESEARCH/IMSGC.HTML)

## National Poll: Quality of Life Has Been Improved by Medical Research:

*Thinking of the last decade, would you say that your quality of life has been improved by medical research?*



SOURCE: A NATIONAL RESEARCH!AMERICA POLL OF LIKELY VOTERS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN AUGUST 2012

## The Bottom Line:

Medical research has advanced our understanding of MS, allowing for new treatments and diagnostics. However, more research is desperately needed for the hundreds of thousands of Americans currently faced with progressively declining health due to their MS. With future advances in prevention and treatment, we can dramatically reduce or eliminate the significant physical and cognitive effects of MS, lower the cost burden of this disease, and promote the independence of those affected by MS. Investing in MS research today can pay off in dramatic ways tomorrow.

## Researcher Testimonial:

*"Support for research on MS is critical in order to stop this devastating disease of young adults that robs them of their ability to work and raise families. While we have made much progress in the last two decades, we still do not have a cure. There remains a critical need for safer and better-tolerated therapies for MS. In addition, we must now also seek to restore function to those already affected by MS. New understanding about the potential for remyelination in the brain holds promise that we may actually be able to promote tissue repair and thereby improve function in advanced stages of the disease. However, with NIH funding lines for neurological diseases at the 12th percentile, some of the promising avenues may never be explored."*



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