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Health-care reform desperately needed by people living with MS

Challenges of living with MS highlighted during MS Awareness Week, March 2-8

PHILADELPHIA – President Obama's plan to overhaul the U.S. health-care system to provide coverage for 48 million uninsured Americans would bring welcome support for people struggling to pay their medical bills while living with MS.

Multiple sclerosis, a chronic neurological disease, costs individuals nearly $70,000 per year in health-care costs such as medication, lost wages and caregiver expenses. Across a lifetime, that can add up to nearly $3 million for people with MS and their families.

Coupled with recent research by the Kaiser Family Foundation, these numbers paint a dramatic picture of the disruptive effects MS can have on the finances of people affected by the disease and how Americans living with chronic illness are struggling to make ends meet.

According to a recent Kaiser poll, about one in three Americans report that their families have had problems paying medical bills in the past year. Nearly half report someone in their family skipping pills or postponing or cutting back on medical care they needed in the past year due to the cost of care.

This type of cost-cutting could be devastating for someone living with MS, yet the therapies' price tag sometimes makes it necessary. While new disease-modifying therapies are successful at slowing the progression of MS for many people, they and other drugs aimed at easing MS symptoms cost an average of $15,172 per year. While Medicare will cover many of these costs for people living with MS, applicants must first cope with a two-year waiting period.

Jeff Rubin of Philadelphia lost his job shortly after being diagnosed with MS, and with it, his health insurance. Without coverage for necessary medication, physical therapy and medical tests during the Medicare waiting period, his family of six's finances quickly spiraled downward. They ultimately were forced to file for bankruptcy, losing many of their assets, including their home and car.

"It's really difficult to try to keep moving and keep up with all of the medicines and rent and utilities," Rubin said. "You're just making it by the skin of your teeth."

Facing ever-worsening symptoms such as blurry vision, dizziness and hearing loss, he had to choose which medicines to take as directed and which of his 16 prescriptions he could take less often to save money. He figured he could skimp on his medications for migraine headaches and depression, but deemed necessary his MS therapy and drugs that fight fatigue, pain and tremors.

“Going on a medication and going off it, I know it can’t be good,” he said. “But sometimes you just don’t have a choice. You just can’t afford it.”

MS Awareness Week, held March 2-8, is an outreach effort to increase public awareness of the daily challenges of living with MS. The Greater Delaware Valley Chapter of the National MS Society funds research, programs and services to help families and individuals overcome these challenges through community events such as Walk MS, coming up at 16 sites throughout the region on April 26 and May 3. Learn more at walk4MS.org.

While the Society does not have the resources necessary to fund individual health-care costs, it offers employment counseling; health insurance advocacy; help paying for home care assistance, emergency needs and home and vehicle modifications; and numerous other services to address the concerns of people diagnosed with this complex disease. Learn more at www.nationalMSsociety.org/pae.

The Costs of MS
(2007 dollars)

Lost Wages	$26,671
Informal Caregiving	$11,162
Paid Caregiving	$2,157
Hospital Costs	$4,997
Physician Costs	$2,671
Medications	$15,172
Retraining	$1,945
Other	$762
Home and Automobile Alterations and Special Equipment	$1,481
Nursing Home Care	$2,100
Total Health-Care Costs	$38,866
Total	**$69,118**