

November 16, 2015

The Honorable Sylvia Mathews Burwell, Secretary  
Department of Health and Human Services  
200 Independence Avenue SW  
Washington, DC 20201

Andy Slavitt  
Acting Administrator  
Centers for Medicare and Medicaid Services  
Department of Health and Human Services  
201 Independence Avenue, SW Room 445-G  
Washington, D.C. 20201

***Re: Texas Proposal to Extend its Section 1115 Medicaid Demonstration Project***

Dear Secretary Burwell and Acting Administrator Slavitt:

I thank you for you the opportunity to share the National MS Society's support for and concerns about the Texas Healthcare Transformation and Quality Improvement Program 1115 demonstration waiver (Waiver) and why access to health care is critical for low-income Texans living with multiple sclerosis (MS).

MS is a chronic, unpredictable, often disabling disease of the central nervous system. MS interrupts the flow of information within the brain, spinal cord and optic nerves resulting in loss of function and symptoms ranging from numbness and tingling to blindness and paralysis. The overall employment rate for people living with MS is between 30% - 45%; within five years of diagnosis, the majority of people with MS are no longer able to work due to disease progression and disability. With the average annual health care cost for someone living with MS in the US at \$70,000, it is financially-devastating for an individual to lose their income while trying to manage one of the most expensive chronic diseases to treat. Some people with MS are left with a financial situation so dire that access to health care is virtually impossible.

Low-income Texans living with MS in the coverage gap are particularly vulnerable to disease progression because without health insurance, they are not able to access the health care and treatments necessary to modify or slow the disease course, treat relapses and manage symptoms. That is why we strongly support an extension of the Waiver – low-income Texans living with MS and other chronic illnesses depend on the safety net that is, in part, funded by the Waiver.

However, only hospitals and participating providers with access to a source of matching funds are able to access Waiver dollars, leaving many areas of Texas that most need the funding unable to access care. We hope this renewal process will be an opportunity for HHS, CMS and Texas leadership to find a more equitable solution to waiver funding disbursement.

Like many other health advocacy organizations, we are concerned that without a plan to close the coverage gap in Texas, Waiver funds may be reduced or jeopardized. We strongly believe that pairing the Waiver funds with coverage expansion would allow Texas to maximize federal funding for health

care and provide the best quality health care for all Texans, including those living with a chronic illness like MS.

We hope that federal and state leaders can move Texas Medicaid away from inequitable funding and a “Band-Aid” approach to uncompensated care toward comprehensive coverage, adequate reimbursement rates and a truly statewide program. However, we advise moving cautiously to a compromise to avoid a crisis in Texas’ already fragile safety net. The impact of losing care for low-income Texans living with MS – who already face significant challenges managing their disease without health insurance – would be disastrous.

We respectfully urge HHS and CMS to continue to work with Texas leadership to maximize all available federal funds to connect low-income Texans with access to health care by approving the renewal of the 1115 Transformation Waiver and by working to create a viable plan to provide health care coverage to Texans who currently fall into the coverage gap.

Thank you again for this opportunity to provide comments.

Sincerely,

Simone Nichols-Segers  
National MS Society, South Central Region  
9600 N Mopac, Suite 150  
Austin, TX 78759  
512.340.2707  
[Simone.Nichols-Segers@nmss.org](mailto:Simone.Nichols-Segers@nmss.org)