



NEW YORK STATE SENATOR
Shelley B. Mayer

\$200,000 State Grant for the ALS Association Greater New York Chapter

SHELLEY B. MAYER October 30, 2019

| ISSUE: **ALS, GRANT FUNDING**



WHITE PLAINS, NY -- On Wednesday, October 30th, Senate Majority Leader Andrea Stewart-Cousins and State Senator Shelley Mayer gathered with local ALS advocate Pat Quinn and others at Burke Rehabilitation Hospital to announce \$200,000 in funding for the ALS Association Greater New York Chapter.

The funding will be used to support care services for people living with ALS and their families through the ALS Association's Care Service Program. The program provides high quality and personalized direct care for ALS patients and support for their families, enabling them to have a better quality of life during the progression of the disease. More commonly referred to as Lou Gehrig's Disease, ALS is a progressive neurodegenerative disease that

affects motor neurons in the brain and the spinal cord. As these cells die, the person loses muscle control and voluntary movement, including ability to speak. During advanced stages of the disease, many patients are paralyzed, yet their minds remain alert.

Senate Majority Leader Andrea Stewart-Cousins said, “Amyotrophic Lateral Sclerosis (ALS) is a devastating disease that affects thousands of families in the U.S. ALS progressively takes away a patient’s physical abilities, and families face significant costs for medical care, equipment, and home health care. This \$200,000 in state funding for the ALS Association Greater New York Chapter will provide high quality support care services to ease the pain of those living with ALS and their families throughout New York State. I am pleased to help secure this needed funding and we will continue to fight for those battling this disease and for their caregivers. This is a continuation of our commitment to help fight ALS.”

In 2018, Senator Mayer sponsored a bill, S.8582, now New York State law, which allows people to donate to the ALS Association directly through a check-off box on the corporate and personal income tax form.

State Senator Shelley B. Mayer said, “I am glad to work with Majority Leader Andrea Stewart-Cousins to secure \$200,000 in funding for the ALS Association Greater New York Chapter. This new funding will support critical services for people living with ALS and their family members. Anything we can do to make their lives easier and provide some relief, while we work towards prevention and a cure, is a step in the right direction. I want to thank my friend Pat Quinn for his herculean efforts to increase awareness and fundraise for ALS research and services. Pat showed the depth of his courage when he turned a life changing diagnosis into steadfast commitment and advocacy.”

Kristen Cocoman, President & CEO, the ALS Association Greater New York Chapter, said “The Upstate and Greater New York Chapters of The ALS Association are incredibly grateful to Majority Leader Andrea Stewart-Cousins and Senator Shelley Mayer for their dedication to the ALS community. The \$200k in funding that we have received as a result of their incredible efforts will be used to provide care and support to ALS patients and families throughout New York State.”

The cornerstone of the ALS Association’s Care Service Program is the Regional Care team model. Each member of the ALS patient care team is specially trained to deal with the unique issues associated with living with ALS. These comprehensive teams consist of nurses,

social workers and assistive technology specialists, providing ongoing proactive assessments of each patient's current needs, conditions, and future risks. As a cohesive team, they educate patients about the full range of essential services available, navigate care needs, and continually manage the progression of the illness. Across New York State, they provide patient care services through home visits, equipment loans, support groups, patient transportation, visits to multidisciplinary treatment centers, and respite support.

Burke Rehabilitation Hospital hosts the White Plains ALS Support Group at their facilities. The group began meeting at Burke in July of 2012.

"As a leader in rehabilitative care, all of us at Burke Rehabilitation Hospital know the toll a life-changing condition like ALS can have on the patient and their families and loved ones. We also know that patient outcomes improve when we care for and support those who care for our patients," **Burke President and CEO Jeffrey Menkes** said. "That's why the grant funding secured by Majority Leader Andrea Stewart-Cousins and Senator Shelley Mayer for the ALS Association, Greater New York Chapter is so vital. This funding will undoubtedly help to enhance the lives of the families who continue to battle this neurodegenerative disease."

A Yonkers native, Mr. Quinn is recognized as one of the co-founders of the ALS Ice Bucket Challenge that resulted in over \$115 million in donations for ALS research and support services.

Pat Quinn, Co-Creator of the Ice Bucket Challenge, said, "ALS is a ruthless disease with no cure and extremely limited treatment options. The care for ALS patients can be an incredible burden on a family. Support is urgent. Support is necessary. The NY state budget finding room to allocate 200 thousand dollars, especially at a time of budgetary cuts, is great news. This is not possible without the continued leadership from my dear friends Senate Majority Leader Andrea Stewart-Cousins and Senator Shelley Mayer. Since the very beginning, both of these incredible women have supported my fight. I can't thank them enough!"

The ALS Association symbolizes the hopes of people everywhere that Amyotrophic Lateral Sclerosis will one day be a disease of the past - relegated to historical status, studied in medical textbooks, conquered by the dedication of thousands who have worked ceaselessly to understand and eradicate this perplexing killer. Until that day comes, the ALS Association relentlessly pursues its mission to help people living with ALS and to leave no stone unturned in search for the cure of the progressive neurodegenerative disease that took the

life and name of Baseball Legend Lou Gehrig. As the only not-for-profit voluntary health agency dedicated solely to the fight against ALS, the ALS Association directs the largest privately-funded research enterprise engaged to uncover the mystery of a disease that affects as many as 30,000 annually. With more than 5,600 people diagnosed each year - an average of 15 new cases each day - the ALS Association's mission is urgent.