

## OPENING STATEMENT

*Patricia Stanco, MHS, Regional Care Manager, The ALS Association Florida Chapter*

Good Afternoon. My name is Patti Stanco, Regional Care Manager with the ALS Association Florida Chapter. We are a nonprofit patient advocacy organization with programs and services to support patients and families with amyotrophic lateral sclerosis – or ALS – better known as Lou Gehrig’s disease.

This year commemorates 75 years since Lou Gehrig delivered his famous farewell speech and there is still no treatment or cure. ALS is a progressive, neurodegenerative disease that strips away a person’s ability to move, speak, swallow, and breathe. Patients live an average of 2-5 years after diagnosis. ALS exacts a tremendous toll on a patient and their family. The difficult journey is a series of losses and a series of victories overcoming obstacles. But the victories are always temporary. A spouse I know recently purchased a countertop microwave so that her husband could reach it from his wheelchair. That worked until he was no longer able to use his hands and had to be fed. That worked until he was unable to swallow and needed a feeding tube.

The financial burdens are a challenge to bear as well. Even with insurance, the cost of home care, co-pays for equipment, and the loss of income when a spouse has to quit working to take care of a loved one all add to an already emotional and stressful situation.

As Regional Care Manager I help to “connect the dots” on that journey. Some of the dots include accessing quality health care through a multidisciplinary ALS clinic, attending resource support groups, scheduling a home visit, getting set up with hospice or home health, or helping to decipher the research lingo on [clinicaltrials.gov](http://clinicaltrials.gov). Research is always a burning question for an ALS patient. “What is out there that I can enroll in that might benefit me?”

What I have a tough time answering is “why.” Why does research take so long? Why are there so few treatments? Why isn’t there more funding? So I look forward to this opportunity to ask some more questions of my own here today. Is there a smarter way to do research? Is there a better way for the FDA to review new drug applications? Is there a common-sense way to improve access to potentially life-saving compounds? The answer is most certainly yes. Rep. Bilirakis recently signed on to the MODDERN CURES Act which would make it easier for pharmaceutical companies to develop so-called dormant compounds that otherwise would not be economically feasible to bring to market without an overdue update to the how the agency classifies compounds. There are certainly other strategies to get “more shots on goal” for research and improve access that are smarter without adding cost and without adding more red tape.

I am always inspired by a sentiment I hear with surprising frequency. A newly diagnosed patient recently said to me “I know it is probably too late for me – but I just do not want anyone else to have to endure this ... and we have to do something.”

I thank Congressman Bilirakis for hosting this important event. I look forward to the discussion today and appreciate the invitation to participate with the other panelists.

Thank you.