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Subject: Photo Op: ALS Proclamation Reading
Location: 1st Floor Lobby, Statehouse
When: 5/12/2015 3:00:00 PM - 3:15:00 PM

APPROVED BY: NH on 4/14

EVENT: Photo Op: ALS Proclamation Reading

DATE: Tuesday, May 12, 2015

TIME: 3:00 PM

LOCATION: 1st Floor Lobby, Statehouse

LOCATION SET-UP: N/A (just a photo opportunity and proclamation reading)

ON-SITE LOCATION CONTACT: Internal

SCHEDULING CONTACT:

Tammy Wallace
Health Care Services Coordinator
Muscular Dystrophy Association
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Columbia, SC 29204
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PRIMARY STAFF: Ashton Lee

ADVANCE STAFF: Zach Pippin

PURPOSE: Gov. Haley will join the Muscular Dystrophy Association (MDA) in declaring the month of May as ALS Awareness Month in South Carolina. The purpose of ALS Awareness Month is to raise awareness of ALS among the public, media, government and medical communities. By building awareness MDA can continue to fund research and provide needed services for individuals with ALS and their families.

PRESS: Yes. ABC will most likely cover because they are partners with MDA.

PUBLIC: Yes.

INVITED BY: Tammy Wallace, Muscular Dystrophy Association

INTRODUCED BY: N/A

LENGTH OF SPEAKING: 3-5 mins

SPEAKING ORDER/LINE-BY-LINE:

Gov. Haley will open with remarks.

Gov. Haley will read the proclamation and present it to the Heath family (Martha Heath is from Easley SC. Martha has ALS and will accepting the proclamation with her husband and daughter.)

Martha Heath will give remarks
Photo Opportunity

PROCLAMATION WORDING:

WHEREAS, amyotrophic lateral sclerosis (ALS), or Lou Gehrig's disease, is a progressive, fatal neurodegenerative disease that affects nerve cells in the brain and spinal cord; and

WHEREAS, there are approximately 30,000 Americans living with ALS, and an estimated 15 people are diagnosed with this disease each day; and

WHEREAS, the symptoms of ALS progress from weakness of the skeletal muscles, especially those of the extremities, to difficulty in swallowing, talking, and breathing, and eventual muscle atrophy, with the patient becoming a functional quadriplegic; and

WHEREAS, ALS does not impact a patient's mental capacity, and those affected remain alert and aware of the loss of motor function and continued deterioration that lead to the inevitable outcome of death; and

WHEREAS, on average, ALS patients survive for only 3 to 5 years following diagnosis; and

WHEREAS, while ALS has no known cause, means of prevention, or cure, aggressive treatment of the symptoms can extend the lives of individuals affected by the disease.

NOW, THEREFORE, I, Nikki R. Haley, Governor of the great State of South Carolina, do hereby proclaim May 2015 as

ALS AWARENESS MONTH

throughout the state and encourage all South Carolinians to work together to raise awareness of this devastating disease, its terrible effect on all those it touches, and the need for continued research into its causes, prevention, and cure.

SUGGESTED TALKING POINTS:

REQUEST:

Dear Governor Haley:

As a concerned citizen and the Health Care Coordinator for the Muscular Dystrophy Association, I see the effects ALS has on individuals and families in South Carolina. I would like to request that you issue a proclamation declaring the month of May as ALS Awareness Month in South Carolina.

ALS is a progressive fatal neurodegenerative disease that attacks nerve cells in the brain and spinal cord; making even the simplest movements – walking, speaking, gesturing nearly impossible. Over 30,000 people in the United States are living with ALS with more being diagnosed every day.

The purpose of ALS Awareness Month would be to raise awareness of ALS among the public, media, government and medical communities. By building awareness we can continue to fund research and provide needed services for individuals with ALS and their families.

I am enclosing a sample proclamation. I would like to request that your office schedule a media event to announce and sign the Proclamation at the State House and ask one of the families living with ALS to speak at the event. It is important to have media coverage for this important event.

I will call your office in a few days to further discuss the proclamation and the media event. Thank you in advance for your consideration and approval of this request. Your help will be greatly appreciated by the individuals and families living with ALS.