

# State of South Carolina

## Governor's Proclamation

WHEREAS, Sanfilippo syndrome is a rare, inherited metabolic disorder; and

WHEREAS, children with Sanfilippo syndrome are missing or do not produce enough of an enzyme essential to the breakdown of sugar molecules and, as a result, toxic cellular debris accumulates in the cells causing progressive neurologic and physical degeneration; and

WHEREAS, due to these grave health consequences, children with Sanfilippo syndrome suffer irreversible brain damage by age six and have a life expectancy ranging from 10 - 20 years; and

WHEREAS, while there is currently no cure for Sanfilippo syndrome, potential treatments that have proven effective in animal studies are ready for clinical trials, offering hope to Eliza O'Neill, her family, and others affected by this devastating condition; and

WHEREAS, time is of the essence for Eliza and other children suffering from this syndrome to quickly begin clinical trials and to increase awareness of and support for research to find a cure.

NOW, THEREFORE, I, Nikki R. Haley, Governor of the Great State of South Carolina, do hereby proclaim October 15, 2013, as

### SANFILIPPO SYNDROME AWARENESS DAY

throughout the State and encourage all South Carolinians to work together to raise awareness of Sanfilippo syndrome and the need for continued research into a cure for this devastating disease.



A handwritten signature in black ink, reading "Nikki R. Haley".

NIKKI R. HALEY  
GOVERNOR  
STATE OF SOUTH CAROLINA