

Help find a treatment for Spinal Muscular Atrophy, the number one genetic killer of children under two

Cosponsor the SMA Treatment Acceleration Act

Dear Colleague:

We are writing to urge you to cosponsor the SMA Treatment Acceleration Act, legislation to help find a treatment or cure for Spinal Muscular Atrophy (SMA), the number one genetic killer of children under the age of two.

SMA is an inherited disease that destroys the nerves controlling muscle movement, which affects crawling, walking, head and neck control, swallowing, and even breathing. The gene mutation that causes SMA is carried by one in every 40 people, or approximately 7.5 million Americans. Each child born of two carriers of the mutant gene has a one in four chance of developing SMA.

Researchers have identified the gene responsible for SMA, as well as a disease modifying “back-up” gene that has opened the door to promising new treatment pathways. This research is providing groundbreaking data for SMA and other neurodegenerative disorders, including the muscular dystrophies, Freidrich’s Ataxia, Fragile X syndrome, and Huntington’s disease.

A broad coalition, including FightSMA, Families of SMA, the SMA Foundation, and the Muscular Dystrophy Association, hopes to build on the progress being made by investigators and bring treatments to children affected by SMA. These organizations have united behind the SMA Treatment Acceleration Act, legislation aimed primarily at establishing a national clinical trials network for SMA.

To cosponsor this important legislation, please contact Laurel Havas (Kennedy) at laurel.havas@mail.house.gov or Lindsay Shore (Cantor) at lindsay.shore@mail.house.gov.

Sincerely,

Patrick J. Kennedy
Member of Congress

Eric Cantor
Member of Congress