



September 28, 2017

Governor Edmund G. Brown, Jr.
California State Capitol, Suite 1173
Sacramento, CA 95814

SB 643 (Pan): Holden-Moscone-Garamendi Genetically Handicapped Persons Program: Duchenne Muscular Dystrophy
AAP-CA Position: SUPPORT

Dear Governor Brown:

The American Academy of Pediatrics, California (AAP-CA), representing over 5,000 California pediatricians, strongly supports the proposed legislation SB 643 (Pan). This bill would add Duchenne muscular dystrophy to the list of conditions eligible for the Holden-Moscone-Garamendi Genetically Handicapped Persons Program, which provides medical care and social support services for people with genetically handicapping diseases.

Duchenne is an early onset, severely incapacitating disease that can definitively be diagnosed around 5 or 6 years of age. Children with Duchenne currently receive specialized coordinated care through the California Children's Services (CCS) program, but this coverage only lasts until they age out at 21. At the same time, medical advances have greatly improved the longevity of Duchenne patients, so that now many may expect to live into their 40s. While children with Duchenne can now hope to enjoy much longer lifespans, they must also face the prospect of navigating the healthcare system without specialized support once they become adults.

SB 643 (Pan) would help ensure continuity of care for children suffering from Duchenne as they grow into adults by adding Duchenne to the list of medical conditions eligible for the Holden-Moscone-Garamendi Genetically Handicapped Persons Program, which would provide them with complete coordinated care. This would improve healthcare for Duchenne sufferers and relieve stress for both youth with Duchenne at the cusp of losing their CCS eligibility and their families.

California pediatricians respectfully request that you sign SB 643 (Pan) into law. We thank you for your public service and leadership on behalf of the health and wellbeing of children, youth, and families in California.

Sincerely,

A handwritten signature in black ink, appearing to read 'M. Patel', written in a cursive style.

Mona Patel, M.D., Fellow of the American Academy of Pediatrics
State Government Affairs Committee, American Academy of Pediatrics, California

CC: Kris Calvin, CEO; AAP-CA Leadership; Lydia Bourne