



April 5, 2017

The Honorable Richard Pan
State Capitol, Room 4070
Sacramento, CA 95814
Fax: (916) 651-4906

RE: SB 643 (Pan): The Holden-Moscone-Garamendi Genetically Handicapped Persons Program: Duchenne muscular dystrophy

AAP-CA Position: SUPPORT

Dear Senator Pan:

The American Academy of Pediatrics, California (AAP-CA), representing over 5,000 California pediatricians, strongly supports your 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 be definitively 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.

Pediatricians strongly support SB 643 (Pan). We thank you for your public service and for your leadership on behalf 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