ADDRESS THE UNMET NEEDS OF CHILDREN AND ADULTS WITH SMA

Support DOD Peer Reviewed Medical Research in Spinal Muscular Atrophy

DID YOU KNOW?

- Spinal muscular atrophy (SMA) is an inherited neurodegenerative disease that impacts residents in all 50 states. SMA attacks the nervous system and destroys the muscles used for activities such as breathing, eating, crawling, and walking. (Source: Cure SMA)
- About 1 in 50 Americans is an SMA carrier, including an estimated 384,000 military service members and veterans. If both parents are carriers, every child they have together has a 1 in 4 chance of having SMA. (Source: Cure SMA)
- Due to SMA's rapid muscle loss, 82% of individuals with SMA utilize a wheelchair or other durable medical equipment, 75% depend on 20 or more hours of weekly caregiving assistance, and 36% require breathing support. The SMA community seeks new treatments that increase muscle strength, improve motor function, reduce fatigue, enhance breathing and swallowing, and decrease dependency on mobility devices. (Source: State of SMA Report)
- Congress established the Peer Reviewed Medical Research Program (PRMRP) to foster novel approaches to biomedical research and enhance the health and well-being of service members, veterans, and their families, including those impacted by SMA, a previous PRMRP research priority. (Source: U.S. Department of Defense)

WHY CONGRESS SHOULD ACT

Federal research investments in SMA have led to multiple disease-modifying treatments for SMA and breakthroughs benefiting other neurological and neuromuscular disorders, including amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS). While existing SMA treatments help slow or stop future motor neuron loss and muscle decline, they do not cure the disease or reverse devasting symptoms that cause severe muscle weakness or motor function loss. These devasting symptoms impede the health and independence of children and adults with SMA in all 50 states and especially burdens military and veteran families affected by SMA by impacting their military careers, limiting military spouses, and straining their family budgets. New research through the Peer Reviewed Medical Research Program that focuses on regenerating nerve damage, reversing muscle weakness, and restoring motor function, among other things, will benefit children and adults with SMA and help address the needs of military service members and others who experienced spinal cord injuries, nerve damage, and related muscle disorders.

CURE SMA POSITION

To help address the ongoing and significant unmet needs of individuals with SMA, ***Cure SMA urges Congress to support report language in the Defense Appropriations bill adding "spinal muscular atrophy" in the list of diseases eligible within the U.S. Department of Defense's Peer Reviewed Medical Research Program.*** SMA was last identified as a PRMRP research priority in the **FY 2020** conference report.

Additionally, we support robust funding for all federal research programs (DOD, National Institutes of Health, and the National Science Foundation) to maintain our country's global research leadership and to help unleash innovation that improves the lives of Americans, including individuals suffering from debilitating diseases such as SMA.

cure SMA®

Cure SMA Advocacy | 800-886-1762 | advocacy@cureSMA.org | cureSMA.org

Cure SMA is a national organization that advocates for individuals with spinal muscular atrophy, a progressive neurodegenerative disease that robs people of physical strength, taking away their ability to walk, swallow, and breathe.

DEFENSE APPROPRIATIONS REQUEST INFORMATION

Appropriations Bill:	**Defense Appropriations Bill**
Federal Department:	**U.S. Department of Defense**
Agency/Account:	**Other Department of Defense Programs/ Defense Health Program**
Line Item/ Number:	**Peer Reviewed Medical Research Program/ 150**
Cure SMA Request:	**Report Language (see below)**

CURE SMA REPORT LANGUAGE REQUEST

Within the report related to the Peer-Reviewed Medical Research Program, we ask that "spinal muscular atrophy" be added in the list of priority research areas for the program.

> The Committee directs the Secretary of Defense, in conjunction with the Service Surgeons General, to select medical research projects of clear scientific merit and direct relevance to military health. Research areas considered under this funding are restricted to: …**spinal muscular atrophy.** The Committee emphasizes that the additional funding provided under the Peer-Reviewed Medical Research Program shall be devoted only to the purposes listed above.

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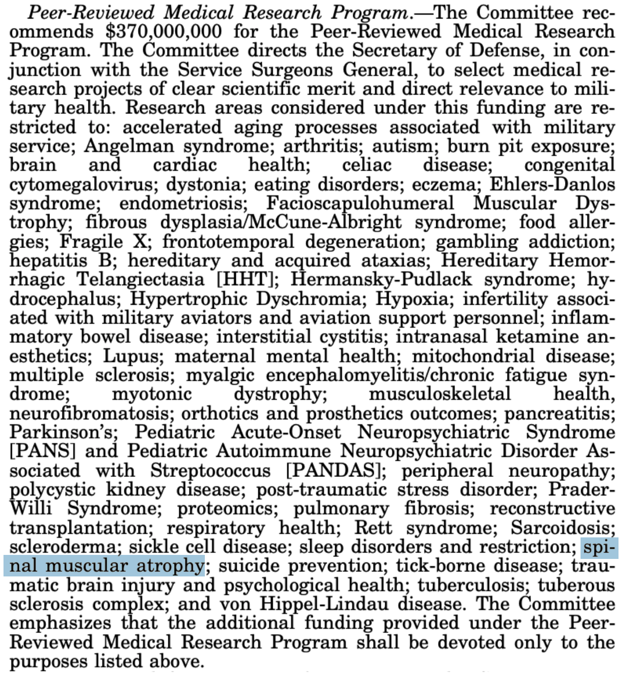

Peer-Reviewed Medical Research Program.—The Committee recommends $370,000,000 for the Peer-Reviewed Medical Research Program. The Committee directs the Secretary of Defense, in conjunction with the Service Surgeons General, to select medical research projects of clear scientific merit and direct relevance to military health. Research areas considered under this funding are restricted to: accelerated aging processes associated with military service; Angelman syndrome; arthritis; autism; burn pit exposure; brain and cardiac health; celiac disease; congenital cytomegalovirus; dystonia; eating disorders; eczema; Ehlers-Danlos syndrome; endometriosis; Facioscapulohumeral Muscular Dystrophy; fibrous dysplasia/McCune-Albright syndrome; food allergies; Fragile X; frontotemporal degeneration; gambling addiction; hepatitis B; hereditary and acquired ataxias; Hereditary Hemorrhagic Telangiectasia [HHT]; Hermansky-Pudlack syndrome; hydrocephalus; Hypertrophic Dyschromia; Hypoxia; infertility associated with military aviators and aviation support personnel; inflammatory bowel disease; interstitial cystitis; intranasal ketamine anesthetics; Lupus; maternal mental health; mitochondrial disease; multiple sclerosis; myalgic encephalomyelitis/chronic fatigue syndrome; myotonic dystrophy; musculoskeletal health, neurofibromatosis; orthotics and prosthetics outcomes; pancreatitis; Parkinson's; Pediatric Acute-Onset Neuropsychiatric Syndrome [PANS] and Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus [PANDAS]; peripheral neuropathy; polycystic kidney disease; post-traumatic stress disorder; Prader-Willi Syndrome; proteomics; pulmonary fibrosis; reconstructive transplantation; respiratory health; Rett syndrome; Sarcoidosis; scleroderma; sickle cell disease; sleep disorders and restriction; spinal muscular atrophy; suicide prevention; tick-borne disease; traumatic brain injury and psychological health; tuberculosis; tuberous sclerosis complex; and von Hippel-Lindau disease. The Committee emphasizes that the additional funding provided under the Peer-Reviewed Medical Research Program shall be devoted only to the purposes listed above.

The language can also be found at this link: https://www.congress.gov/119/crpt/srpt52/CRPT-119srpt52.pdf#page=218