CONCURRENT RESOLUTION

Expressing the sense of Congress regarding the need for further study of the neurological disorder dystonia.

Whereas dystonia is a neurological disorder characterized by powerful and painful involuntary muscle spasms that cause twisting, repetitive muscle movements, and sustained postural deformities;

Whereas dystonia can affect many muscle groups simultaneously;

Whereas several forms of dystonia are genetically inherited, while other forms are considered secondary dystonia due to birth injury, physical trauma, exposure to certain medications, surgery, or stroke;

Whereas there is no known cure for dystonia and though treatments are available, current medical therapies only
superficially address symptoms without curing the actual disease;

Whereas individuals of all ages, genders, and ethnic backgrounds are affected by dystonia;

Whereas dystonia is the third most common movement disorder and affects many more people than better known disorders such as Huntington’s disease, muscular dystrophy, and Lou Gehrig’s disease (amyotrophic lateral sclerosis);

Whereas dystonia affects an estimated 300,000 people in North America;

Whereas many individuals who suffer from dystonia are alienated from their communities and the workplace, causing such individuals to experience isolation and psychological distress and creating the need for greater public awareness, understanding, and tolerance;

Whereas additional research is needed to better understand the connection between the onset of dystonia and a traumatic brain injury due to the increasing prevalence of dystonia amongst combat veterans; and

Whereas the Dystonia Advocacy Coalition has requested that the Congress designate the first week in June as Dystonia Awareness Week in order to educate communities across the Nation about dystonia and the need for research funding, early detection methods, effective treatments, and prevention programs: Now, therefore, be it

1 Resolved by the House of Representatives (the Senate concurring), That it is the sense of Congress that—
(1) the Director of the National Institutes of Health (NIH) shall take a leadership role in the fight against dystonia by—

(A) continuing the current collaboration between the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), and the National Eye Institute with respect to dystonia;

(B) encouraging NINDS and NIDCD to provide the necessary funding for intramural and extramural biomedical research and education with respect to dystonia through the co-sponsorship of workshops and seminars with respected patient organizations;

(C) exploring collaborative opportunities for dystonia research at the John Edward Porter Neuroscience Research Center at the National Institutes of Health and pursuing more aggressive programs in dystonia research using the multidisciplinary approach of the Center; and

(D) exploring collaborative opportunities to expand the dystonia research portfolio through the Office of Rare Diseases;
(2) funding should be increased for basic biomedical research for dystonia as well as other neurological disorders through the National Institutes of Health;

(3) further research is needed to identify an accurate diagnostic test for dystonia and an epidemiological study should be conducted to determine the frequency of the disease in the population;

(4) patient access to safe and effective dystonia therapies such as botulinum toxin injections should be improved; and

(5) public awareness and professional education regarding dystonia needs to increase through partnerships between the Federal Government and patient advocacy organizations.