

111TH CONGRESS
1ST SESSION

H. CON. RES. 134

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

IN THE HOUSE OF REPRESENTATIVES

MAY 21, 2009

Mr. DAVIS of Illinois submitted the following concurrent resolution; which was referred to the Committee on Energy and Commerce

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*
- 2 *concurring), That it is the sense of Congress that—*

1 (1) the Director of the National Institutes of
2 Health (NIH) shall take a leadership role in the
3 fight against dystonia by—

4 (A) continuing the current collaboration
5 between the National Institute of Neurological
6 Disorders and Stroke (NINDS), the National
7 Institute on Deafness and Other Communica-
8 tion Disorders (NIDCD), and the National Eye
9 Institute with respect to dystonia;

10 (B) encouraging NINDS and NIDCD to
11 provide the necessary funding for intramural
12 and extramural biomedical research and edu-
13 cation with respect to dystonia through the co-
14 sponsorship of workshops and seminars with re-
15 spected patient organizations;

16 (C) exploring collaborative opportunities
17 for dystonia research at the John Edward Por-
18 ter Neuroscience Research Center at the Na-
19 tional Institutes of Health and pursuing more
20 aggressive programs in dystonia research using
21 the multidisciplinary approach of the Center;
22 and

23 (D) exploring collaborative opportunities to
24 expand the dystonia research portfolio through
25 the Office of Rare Diseases;

1 (2) funding should be increased for basic bio-
2 medical research for dystonia as well as other neuro-
3 logical disorders through the National Institutes of
4 Health;

5 (3) further research is needed to identify an ac-
6 curate diagnostic test for dystonia and an epidemio-
7 logical study should be conducted to determine the
8 frequency of the disease in the population;

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

12 (5) public awareness and professional education
13 regarding dystonia needs to increase through part-
14 nerships between the Federal Government and pa-
15 tient advocacy organizations.

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