

109TH CONGRESS  
1ST SESSION

# H. CON. RES. 122

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

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## IN THE HOUSE OF REPRESENTATIVES

APRIL 5, 2005

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

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## 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; and

Whereas the National Institutes of Health recently issued a program announcement entitled "Studies Into the Causes and Mechanisms of Dystonia" to support the study of dystonia: Now, therefore, be it

1       *Resolved by the House of Representatives (the Senate*  
2   *concurring), That it is the sense of Congress that—*

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

6                   (A) continuing the current collaboration  
7                   between the National Institute of Neurological  
8                   Disorders and Stroke (NINDS), the National  
9                   Institute on Deafness and Other Communica-

3 (B) encouraging NINDS and NIDCD to  
4 provide the necessary funding for intramural  
5 and extramural biomedical research and edu-  
6 cation with respect to dystonia through the co-  
7 sponsorship of workshops and seminars with re-  
8 spected patient organizations; and

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

15 (2) funding should be increased for basic bio-  
16 medical research for dystonia as well as other neuro-  
17 logical disorders through the National Institutes of  
18 Health;

19 (3) further research is needed to identify an ac-  
20 curate diagnostic test for dystonia and an epidemi-  
21 logical study should be conducted to determine the  
22 frequency of the disease in the population;

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

1 (5) public awareness and professional education  
2 regarding dystonia needs to increase through part-  
3 nerships between the Federal Government and pa-  
4 tient advocacy organizations.

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