

would ask that everyone support this legislation, not only because of the issue of pulmonary hypertension and research and the need for it, but also as a tribute to Representative Lantos.

Madam Speaker, I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from New Jersey (Mr. PALLONE) that the House suspend the rules and pass the bill, H.R. 6568, as amended.

The question was taken; and (two-thirds being in the affirmative) the rules were suspended and the bill, as amended, was passed.

A motion to reconsider was laid on the table.

ALS REGISTRY ACT

Mr. PALLONE. Madam Speaker, I move to suspend the rules and pass the Senate bill (S. 1382) to amend the Public Health Service Act to provide for the establishment of an Amyotrophic Lateral Sclerosis Registry.

The Clerk read the title of the Senate bill.

The text of the Senate bill is as follows:

S. 1382

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "ALS Registry Act".

SEC. 2. AMENDMENT TO THE PUBLIC HEALTH SERVICE ACT.

Part P of title III of the Public Health Service Act (42 U.S.C. 280g et seq.) is amended by adding at the end the following:

"SEC. 399R. AMYOTROPHIC LATERAL SCLEROSIS REGISTRY.

"(a) ESTABLISHMENT.—

"(1) IN GENERAL.—Not later than 1 year after the receipt of the report described in subsection (b)(2)(A), the Secretary, acting through the Director of the Centers for Disease Control and Prevention, may, if scientifically advisable—

"(A) develop a system to collect data on amyotrophic lateral sclerosis (referred to in this section as 'ALS') and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS, including information with respect to the incidence and prevalence of the disease in the United States; and

"(B) establish a national registry for the collection and storage of such data to develop a population-based registry of cases in the United States of ALS and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS.

"(2) PURPOSE.—It is the purpose of the registry established under paragraph (1)(B) to—

"(A) better describe the incidence and prevalence of ALS in the United States;

"(B) examine appropriate factors, such as environmental and occupational, that may be associated with the disease;

"(C) better outline key demographic factors (such as age, race or ethnicity, gender, and family history of individuals who are diagnosed with the disease) associated with the disease;

"(D) better examine the connection between ALS and other motor neuron disorders

that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS; and

"(E) other matters as recommended by the Advisory Committee established under subsection (b).

"(b) ADVISORY COMMITTEE.—

"(1) ESTABLISHMENT.—Not later than 180 days after the date of the enactment of this section, the Secretary, acting through the Director of the Centers for Disease Control and Prevention, may establish a committee to be known as the Advisory Committee on the National ALS Registry (referred to in this section as the 'Advisory Committee'). The Advisory Committee shall be composed of not more than 27 members to be appointed by the Secretary, acting through the Centers for Disease Control and Prevention, of which—

"(A) two-thirds of such members shall represent governmental agencies—

"(i) including at least one member representing—

"(I) the National Institutes of Health, to include, upon the recommendation of the Director of the National Institutes of Health, representatives from the National Institute of Neurological Disorders and Stroke and the National Institute of Environmental Health Sciences;

"(II) the Department of Veterans Affairs;

"(III) the Agency for Toxic Substances and Disease Registry; and

"(IV) the Centers for Disease Control and Prevention; and

"(ii) of which at least one such member shall be a clinician with expertise on ALS and related diseases, an epidemiologist with experience in data registries, a statistician, an ethicist, and a privacy expert (relating to the privacy regulations under the Health Insurance Portability and Accountability Act of 1996); and

"(B) one-third of such members shall be public members, including at least one member representing—

"(i) national and voluntary health associations;

"(ii) patients with ALS or their family members;

"(iii) clinicians with expertise on ALS and related diseases;

"(iv) epidemiologists with experience in data registries;

"(v) geneticists or experts in genetics who have experience with the genetics of ALS or other neurological diseases and

"(vi) other individuals with an interest in developing and maintaining the National ALS Registry.

"(2) DUTIES.—The Advisory Committee may review information and make recommendations to the Secretary concerning—

"(A) the development and maintenance of the National ALS Registry;

"(B) the type of information to be collected and stored in the Registry;

"(C) the manner in which such data is to be collected;

"(D) the use and availability of such data including guidelines for such use; and

"(E) the collection of information about diseases and disorders that primarily affect motor neurons that are considered essential to furthering the study and cure of ALS.

"(3) REPORT.—Not later than 270 days after the date on which the Advisory Committee is established, the Advisory Committee may submit a report to the Secretary concerning the review conducted under paragraph (2) that contains the recommendations of the Advisory Committee with respect to the results of such review.

"(c) GRANTS.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, may award grants to, and enter into contracts and coop-

erative agreements with, public or private nonprofit entities for the collection, analysis, and reporting of data on ALS and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS after receiving the report under subsection (b)(3).

"(d) COORDINATION WITH STATE, LOCAL, AND FEDERAL REGISTRIES.—

"(1) IN GENERAL.—In establishing the National ALS Registry under subsection (a), the Secretary, acting through the Director of the Centers for Disease Control and Prevention, may—

"(A) identify, build upon, expand, and coordinate among existing data and surveillance systems, surveys, registries, and other Federal public health and environmental infrastructure wherever possible, which may include—

"(i) any registry pilot projects previously supported by the Centers for Disease Control and Prevention;

"(ii) the Department of Veterans Affairs ALS Registry;

"(iii) the DNA and Cell Line Repository of the National Institute of Neurological Disorders and Stroke Human Genetics Resource Center at the National Institutes of Health;

"(iv) Agency for Toxic Substances and Disease Registry studies, including studies conducted in Illinois, Missouri, El Paso and San Antonio, Texas, and Massachusetts;

"(v) State-based ALS registries;

"(vi) the National Vital Statistics System; and

"(vii) any other existing or relevant databases that collect or maintain information on those motor neuron diseases recommended by the Advisory Committee established in subsection (b); and

"(B) provide for research access to ALS data as recommended by the Advisory Committee established in subsection (b) to the extent permitted by applicable statutes and regulations and in a manner that protects personal privacy consistent with applicable privacy statutes and regulations.

"(2) COORDINATION WITH NIH AND DEPARTMENT OF VETERANS AFFAIRS.—Consistent with applicable privacy statutes and regulations, the Secretary may ensure that epidemiological and other types of information obtained under subsection (a) is made available to the National Institutes of Health and the Department of Veterans Affairs.

"(e) DEFINITION.—For the purposes of this section, the term 'national voluntary health association' means a national non-profit organization with chapters or other affiliated organizations in States throughout the United States with experience serving the population of individuals with ALS and have demonstrated experience in ALS research, care, and patient services."

SEC. 3. REPORT ON REGISTRIES.

Not later than 18 months after the date of enactment of this Act, the Secretary of Health and Human Services may submit to the appropriate committees of Congress a report outlining—

- (1) the registries currently under way;
- (2) future planned registries;
- (3) the criteria involved in determining what registries to conduct, defer, or suspend; and
- (4) the scope of those registries.

The report may also include a description of the activities the Secretary undertakes to establish partnerships with research and patient advocacy communities to expand registries.

□ 1630

The SPEAKER pro tempore. Pursuant to the rule, the gentleman from

New Jersey (Mr. PALLONE) and the gentleman from Nebraska (Mr. TERRY) each will control 20 minutes.

The Chair recognizes the gentleman from New Jersey.

GENERAL LEAVE

Mr. PALLONE. Madam Speaker, I ask unanimous consent that all Members may have 5 legislative days in which to revise and extend their remarks and include extraneous material on the bill under consideration.

The SPEAKER pro tempore. Is there objection to the request of the gentleman from New Jersey?

There was no objection.

Mr. PALLONE. Madam Speaker, I yield myself such time as I may consume.

Madam Speaker, I rise in support of S. 1382, the ALS Registry Act. ALS, more commonly known as Lou Gehrig's disease, is a fatal, progressive neurodegenerative disease affecting approximately 5,600 Americans each year. It is estimated that as many as 30,000 Americans have ALS at any given time, with an average life expectancy of 2 to 5 years from time of diagnosis.

Today, no single national patient registry collects and stores information on the prevalence and incidence of ALS.

The ALS Registry Act would create a nationwide registry at the Centers for Disease Control and Prevention for ALS and other related motor neuron disorders. The patient registry would collect data which is urgently needed for ALS research, disease management, and the development of standards of care. This will allow us to make real progress in better understanding ALS, and to develop measures for prevention, treatment, and eventually a cure for this dreaded disease.

I would like to thank my dear friend and colleague on the Energy and Commerce Committee Representative ELIOT ENGEL for his dedication to bringing this bill before us today. ELIOT and I, along with NITA LOWEY, started the same time in Congress, which is about 20 years now. I remember when we had the hearing on this. Mr. ENGEL is from New York and talked a little about Lou Gehrig. I had actually been to a Yankees' game just a few days before, and I saw so many people wearing Lou Gehrig shirts, and I was amazed after so many years that that would still be the case.

On October 16 of last year, we overwhelmingly passed the House companion to S. 1382, and I strongly urge us to pass this bill by the same margin. Please join me in enacting this important legislation.

I reserve the balance of my time.

Mr. TERRY. Madam Speaker, I yield myself such time as I may consume.

Madam Speaker, as one of the co-authors of this bill, I rise in support of Senate 1382, or at least the House version of this ALS Registry Act.

ALS, sometimes called Lou Gehrig's disease, is a rapidly progressive and invariably fatal neurological disease that

attacks the nerve cells responsible for controlling voluntary muscles. The disease belongs to a group of disorders known as motor neuron diseases, which are characterized by the gradual degeneration and death of motor neurons.

As many as 20,000 Americans have ALS, and an estimated 5,000 people in the United States are diagnosed with the disease each year. ALS is one of the most common neuromuscular diseases worldwide, and people of all races and ethnic backgrounds are affected. ALS most commonly strikes people between 40 and 60 years of age, but younger and older people also can develop the disease.

Constituents suffering from what used to be called Lou Gehrig's disease have been visiting Congress and asking for help for years. The disease is brutal, and I believe that establishing a registry will help researchers cure ALS. An ALS registry will serve as an excellent resource for scientists.

I thank Mr. ENGEL and others like Mr. DEAL who helped shepherd this through our subcommittee and committee and in making sure that it got here today.

Madam Speaker, I urge all Members to support this legislation.

I reserve the balance of my time.

Mr. PALLONE. Madam Speaker, I yield 4 minutes to the sponsor of the bill, the gentleman from New York (Mr. ENGEL).

Mr. ENGEL. I thank my good friend, the gentleman from New Jersey (Mr. PALLONE), with whom I have worked so closely during these past 20 years on so many things, and he is doing a wonderful job as chairman of our Health Subcommittee on the Energy and Commerce Committee.

Madam Speaker, I am so proud that through hard work and compromise with the Senate, that today we will take up a final version of the ALS Registry Act. The House has passed this bill before. It was stuck in the Senate. We finally have it shaken loose and it is back with the Senate version which we are proud to all support. Thanks to this legislation, we will provide for the creation and maintenance of a single, nationwide ALS registry at the Centers for Disease Control and Prevention.

Amyotrophic lateral sclerosis, ALS, also known as Lou Gehrig's disease, is a fatal, progressive neurodegenerative disease that affects motor nerve cells in the brain and spinal cord. Approximately 5,600 people in the U.S. are diagnosed with ALS each year, and it is estimated that as many as 30,000 Americans have the disease at any given time. The average life expectancy for a person with ALS is 2 to 5 years from the time of diagnosis. The causes of ALS are not well understood, and there is no known cure.

I first became aware of this disease through my grandmother. My father's mother was diagnosed with this disease. I was only 2½ when she passed away. As Mr. PALLONE mentioned, the most famous person with this disease is

Lou Gehrig. I come from the Bronx where the Yankees play, and Yankee Stadium just had its last game on Sunday evening. The clips that we saw were from that famous speech that Lou Gehrig made at Yankee Stadium. You could hear the echoes reverberating, saying that he felt he was the luckiest man on the face of the Earth. And it is fitting that today we pass this bill, just a few days after Yankee Stadium where Lou Gehrig toiled for so many years is closing. This is a fitting tribute to Lou Gehrig.

A single national patient registry which collects and stores information on the prevalence and incidence of ALS does not exist in the United States today, believe it or not, and that is what this bill is going to change.

The establishment of a national registry will help identify the incidence and prevalence of ALS and other motor neuron disorders in the United States and collect data which is urgently needed for ALS research, disease management and the development of standards of care in order to significantly enhance the Nation's efforts to find a treatment and cure for ALS.

I would like to thank Steve Gibson and Pat Wildman of the ALS Association for their partnership on this bill. We have worked with them for so many years, as well as William Garner of Chairman DINGELL's staff for his work on this bill. I would also like to thank John Ford, formerly of Chairman DINGELL's staff and Katherine Martin, formerly of Ranking Member BARTON's staff who worked so diligently on this bill prior to its original House passage in 2007.

I thank all my colleagues for it and urge them to pass this bill. It has been a long time coming, but it is finally here.

Mr. TERRY. Madam Speaker, I have no further speakers, and I yield back the balance of my time.

Mr. PALLONE. Madam Speaker, I would just urge passage of this important legislation relevant to ALS, and I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from New Jersey (Mr. PALLONE) that the House suspend the rules and pass the Senate bill, S. 1382.

The question was taken.

The SPEAKER pro tempore. In the opinion of the Chair, two-thirds being in the affirmative, the ayes have it.

Mr. TERRY. Madam Speaker, I object to the vote on the ground that a quorum is not present and make the point of order that a quorum is not present.

The SPEAKER pro tempore. Pursuant to clause 8 of rule XX and the Chair's prior announcement, further proceedings on this motion will be postponed.

The point of no quorum is considered withdrawn.