## TOM LANTOS PULMONARY HYPERTENSION RESEARCH AND EDUCATION ACT OF 2008

Mr. PALLONE. Madam Speaker, I move to suspend the rules and pass the bill (H.R. 6568) to direct the Secretary of Health and Human Services to encourage research and carry out an educational campaign with respect to pulmonary hypertension, and for other purposes, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 6568

*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 ''Tom Lantos Pulmonary Hypertension Research and Education Act of 2008''.

**SEC. 2. TABLE OF CONTENTS.**

The table of contents for this Act is as follows:

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**TITLE I—RESEARCH ON PULMONARY HYPERTENSION**

**SEC. 101. EXPANSION AND INTENSIFICATION OF ACTIVITIES.**

(a) SENSE OF CONGRESS.—It is the sense of the Congress that—

(1) the Secretary of Health and Human Services (in this Act referred to as the ''Secretary''), acting through the Director of the National Institutes of Health and the Director of the National Heart, Lung, and Blood Institute (in this title referred to as the ''Institute''), should continue aggressive work on pulmonary hypertension;

(2) as part of such work, the Director of the Institute should continue research to expand the understanding of the causes of, and to find a cure for, pulmonary hypertension; and

(3) activities under paragraph (1) may include conducting and supporting—

(A) basic research concerning the etiology and causes of pulmonary hypertension;

(B) basic research on the relationship between scleroderma, sickle cell anemia (and other conditions identified by the Director of the Institute that can lead to a secondary diagnosis of pulmonary hypertension), and pulmonary hypertension;

(C) clinical research for the development and evaluation of new treatments for pulmonary hypertension, including the establishment of a ''Pulmonary Hypertension Clinical Research Network'';

(D) support for the training of new clinicians and investigators with expertise in the pulmonary hypertension; and

(E) information and education programs for the general public.

(b) BIENNIAL REPORTS.—As part of the biennial report made under section 403 of the Public Health Service Act (42 U.S.C. 283), the Secretary shall include information on the status of pulmonary hypertension research at the National Institutes of Health.

**TITLE II—INCREASING AWARENESS OF PULMONARY HYPERTENSION**

**SEC. 201. PROMOTING PUBLIC AWARENESS.**

(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall carry out an educational campaign to increase public awareness of pulmonary hypertension. Print, video, and Web-based materials distributed under this program may include—

(1) basic information on pulmonary hypertension and its symptoms; and

(2) information on—

(A) the incidence and prevalence of pulmonary hypertension;

(B) diseases and conditions that can lead to pulmonary hypertension as a secondary diagnosis;

(C) the importance of early diagnosis; and

(D) the availability, as medically appropriate, of a range of treatment options and pulmonary hypertension.

(b) DISSEMINATION OF INFORMATION.—The Secretary is encouraged to disseminate information under subsection (a) through a cooperative agreement with a national nonprofit entity with expertise in pulmonary hypertension.

(c) REPORT TO CONGRESS.—Not later than September 30, 2009, the Secretary shall report to the Committee on Energy and Commerce of the House of Representatives, the Committee on Health, Education, Labor, and Pensions of the Senate, and the Committee on Appropriations of the House of Representatives and the Senate on the status of activities under this section.

(d) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there is authorized to be appropriated $2,500,000 for each of fiscal years 2009, 2010, and 2011.

**SEC. 202. PROMOTING AWARENESS AMONG HEALTH CARE PROFESSIONALS.**

(a) IN GENERAL.—The Secretary, acting through the Administrator of the Health Resources and Services Administration and the Director of the Centers for Disease Control and Prevention, shall carry out an educational campaign to increase awareness of pulmonary hypertension among health care providers. Print, video, and Web-based materials distributed under this program may include information on—

(1) the symptoms of pulmonary hypertension;

(2) the importance of early diagnosis;

(3) current diagnostic criteria; and

(4) Food and Drug Administration-approved therapies for the disease.

(b) TARGETED HEALTH CARE PROVIDERS.—Health care providers targeted through the campaign under subsection (a) shall include, but not be limited to, cardiologists, pulmonologists, rheumatologists, primary care physicians, pediatricians, and nurse practitioners

(c) DISSEMINATION OF INFORMATION.—The Secretary is encouraged to disseminate information under subsection (a) through a cooperative agreement with a national nonprofit entity with expertise in pulmonary hypertension.

(d) REPORT TO CONGRESS.—Not later than September 30, 2009, the Secretary shall report to the Committee on Energy and Commerce of the House of Representatives, the Committee on Health, Education, Labor, and Pensions of the Senate, and the Committee on Appropriations of the House of Representatives and the Senate on the status of activities under this section.

(e) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there is authorized to be appropriated $2,500,000 for each of fiscal years 2009, 2010, and 2011.

The SPEAKER pro tempore. Pursuant to the rule, the gentleman from New Jersey (Mr. PALLONE) and the gentleman from Georgia (Mr. DEAL) 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 have 5 legislative days to revise and extend their remarks and to 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 strong support of H.R. 6568, the Tom Lantos Pulmonary Hypertension Research and Education Act of 2008, as introduced by representative KEVIN BRADY and my good friend and the Health Subcommittee's vice chair, LOIS CAPPS.

Pulmonary hypertension is a rare lung disorder in which the blood pressure in the pulmonary artery rises far above normal levels, usually with no apparent reason. Symptoms include chronic fatigue, shortness of breath, chest pains, palpitations, and fainting. According to the Centers for Disease Control and Prevention, in 2002 there were 15,668 deaths and 260,000 hospital visits among persons with pulmonary hypertension.

The number of hospitalizations related to pulmonary hypertension has been increasing in recent years, especially among women. This measure would help improve current research efforts on pulmonary hypertension, as well as increased public awareness.

I want to thank my colleagues, Mr. BRADY and Mrs. CAPPS for their work on this legislation.

I also want to recognize my colleague, Mr. Lantos, who passed away earlier this year. Passage of today's bill is a fitting tribute to Representative Lantos and his work in raising awareness about pulmonary hypertension and thousands of patients who suffer from it.

I urge my colleagues on both sides of the aisle to offer their support for this very important bill, and I reserve the balance of my time.

Mr. DEAL of Georgia. Madam Speaker, I too rise in support of this legislation and want to commend the work of Mrs. CAPPS and also Mr. KEVIN BRADY.

I would, at this time, yield to Mr. BRADY as much time as he might consume in support of this legislation, of which he was one of the original sponsors.

Mr. BRADY of Texas. Let me first thank Mr. DEAL for his remarkable leadership in shepherding this bill to the floor. Without him championing it through the Energy and Commerce Committee along with Mrs. CAPPS, this simply would not be happening. I want to thank Mr. DEAL for his leadership on behalf of many, many, many patients.

I would also like to take a brief moment to reflect on the loss of my friend and one of pulmonary hypertension's

most important voices in Congress, Tom Lantos. I know I speak for each one of us here when I say that we have dearly missed Tom's passion for his work and for the House of Representatives.

As chairman of the House Foreign Relations Committee, Tom was regularly confronting some of the most pressing challenges facing our country in the world today. Nevertheless, it was his work on PH that he routinely cited the most important thing he was doing in Congress.

As many of us know, Tom's granddaughter, Charity, was diagnosed with pulmonary hypertension several years ago. Ever since he had been a tireless advocates on behalf of PH patients and, in my opinion, a large part of why we have made so much progress over the last decade.

Like Tom, my involvement with PH is very personal. It is now more than a decade since the daughter of my very good friend, Jack Stibbs, was diagnosed with PH. Jack's daughter, Emily, was only 5 when her parents noticed at a community parade that she was struggling to bicycle fast enough to keep up with her friends. She always seemed out of breath and struggled to climb stairs. Doctors eventually diagnosed her with pulmonary hypertension.

PH is a serious and often-fatal condition where the blood pressure in the lungs rises to dangerously high levels. In PH patients, the walls of the arteries that take blood from the right side of the heart to the lungs, thicken and constrict. As a result, the right side of the heart has to pump harder and harder to move blood into the lungs, causing it to enlarge and ultimately fail.

PH can occur without a known cause or be secondary to other conditions, such as scleroderma, lupus, HIV, sickle cell, and liver disease. Patients develop symptoms that include shortness of breath, fatigue, chest pain, dizziness and fainting.

Unfortunately, these symptoms are frequently misdiagnosed, leaving patients with the false impression that they have a minor pulmonary or cardiovascular condition. By the time many patients receive an accurate diagnosis, the disease has progressed to a late stage, making it impossible to receive a necessary heart or lung transplant.

When Emily Stibbs was first diagnosed in 1977, the average survival rate for PH patients was just 2½ years. There was only one FDA-approved therapy at the time, and the best that doctors could do was to make patients comfortable as their condition deteriorated. To make matters worse, there is very little research on PH being supported by the National Institutes of Health.

Fortunately we have come a very long way in a relatively short period of time. There are now six FDA-approved therapies for PH with many, many more in the pipeline. People are living longer with a better quality of life than ever before. Our Federal health care agencies, including the National Institutes of Health, Centers for Disease Control and Food and Drug Administration are actively and aggressively engaged in the fight against PH.

Those of us here on Capitol Hill are more aware of this disease than ever before. The 247 Representatives who cosponsored our PH bill in the last Congress are testament to that fact. But there is still more work that can and must be done as pulmonary hypertension afflicts over 100,000 Americans and continues to strike women of child-bearing age in growing numbers.

Representative LOIS CAPPS has joined me in introducing the bill before us today, the Tom Lantos Pulmonary Hypertension Research and Education Act. This bill builds on what we have already accomplished and further emphasizes the need for more research, more training and more awareness.

Specifically, it urges the NIH to aggressively pursue collaborative research into better treatments and provides funding to increase physician and public awareness of the disease to ensure early and accurate diagnoses. I am proud of what we have done together and believe that a cure for PH is just around the corner, so long as we continue to keep the National Institutes of Health and medical community focused.

On behalf of pulmonary hypertension patients everywhere, I would like to thank Representative LOIS CAPPS for her leadership of this bill, Energy and Commerce Chairman DINGELL, Ranking Member JOE BARTON, Health Subcommittee Chairman FRANK Pallone, and, as I mentioned before, my dear friend, NATHAN DEAL, again, whose leadership was remarkable.

I conclude with this, over the last 10 years, we have decided that if I did nothing else in Congress, I would find a cure for this incurable disease.

I appreciate so much the Pulmonary Hypertension Association, which has raised, over the years, $10 million for research and education; the chairman of the association, Carl Hicks; its great president, Rino Aldrighetti; Katie Kroner and Gavin Lindberg, who have spent many years advocating on behalf of our patients in the association; Dr. Elizabeth Nabel, director of the National Heart, Lung and Blood Institute, who helped start the first Centers of Excellence for PH at the National Institutes of Health; and finally the staff of the Energy and Commerce Committee, including Jessica McNiece, Aarti Shaw, Brandon Clark, and Ryan Long.

It takes a collaborative effort to tackle a disease like this. We are making progress, and I am eternally grateful for their support.

Mr. PALLONE. Madam Speaker, I yield 2 minutes to the sponsor of the legislation, the gentlewoman from California (Mrs. CAPPS).

Mrs. CAPPS. I thank the chairman of our Health subcommittee for recognizing me.

Madam Speaker, I rise in support of H.R. 6568, for which I am proud to be the lead Democratic sponsor.

I want to commend Congressman KEVIN BRADY for his tireless work on behalf of pulmonary hypertension awareness over the last several years. As the name of this legislation indicates, our dear friend and former colleague, Tom Lantos, was a champion of working against this disease because of a very personal connection, his lovely granddaughter, Charity.

I am so proud that we could help the Lantos family fulfill their goal of seeing this bill acted on during the 110th Congress. I am sure that many of us will remember forever the day that Charity testified, that was in December of 2005.

She testified before the Energy and Commerce Committee. She so eloquently relayed to us the challenges of getting properly diagnosed and then adjusting to her daily complex routine in order to cope with her illness at the same time she pursued her musical career.

Pulmonary hypertension is a very rare disease, which is marked by increased blood pressure in the pulmonary artery, as has been described. There are very few treatments available, and this legislation is aimed at improving research and awareness about the disease so that we can find more effective treatments and, one day, a cure.

I want to thank the Energy and Commerce majority and minority staff for working hard to bring this bill up today, for the ranking member of the minority Health committee for insisting that it come before us today, and for the lead sponsor, again, KEVIN BRADY, for his efforts on behalf of the pulmonary hypertension community.

Of course, we thank the Lantos family for their advocacy on behalf of pulmonary hypertension, and the efforts to ensure this bill's passage in Tom Lantos' memory.

Mr. DEAL of Georgia. Madam Speaker, I had the honor of chairing that hearing that Mrs. CAPPS just referred to back in 2005 in the Energy and Commerce Committee, Health Subcommittee, in which we had the first hearing on pulmonary hypertension. The Honorable Tom Lantos' granddaughter, Charity, did testify. She was a compelling witness, and I think it is altogether fitting that this legislation be named in honor of her grandfather.

I want to thank Mrs. CAPPS and Mr. BRADY and all the others who have worked so hard on this legislation. As Mr. BRADY pointed out, this is an excellent example of citizen advocates who have taken this issue to heart and who have literally pushed this all the way. Without their support, we probably would not have been able to get this legislation to the floor. I commend all those who have had a hand in it.

Madam Speaker, I yield back the balance my time.

Mr. PALLONE. Madam Speaker, I have no further requests for time. I

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 cooperative 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