My legislation would also finance a national public awareness campaign to bring this illness out of the dark and shed new light on how to screen and treat mothers. It would also add depression to the biennial report the National Institutes of Health must submit to the Congress.

Lastly, my bill will finance much-needed grants to public and nonprofit organizations to establish and operate programs that provide screening, treatment and various health care and support services to individuals with postpartum depression or postpartum psychosis.

Moreover, Madam Speaker, this bill is an affordable approach to research and services. The CBO estimates that H.R. 20 costs less than $500,000 per year, and $18 million over 5 years.

This is good policy, Madam Speaker. This is good politics. And this is a good public health bill.

I want to take a moment, Madam Speaker, just to thank the many organizations and groups, groups like Postpartum Support International, whose president right now sits in the gallery, Ms. Susan Stone; the Family Mental Health Foundation; the American Psychological Association; the American Psychiatric Association; the American College of Obstetricians and Gynecologists; and groups like the Children's Defense Fund, the Melanie Blocker-Stokes Foundation, Suicide Prevention Action Network, Planned Parenthood Federation of America Depression and Bipolar Support Alliance, the Mental Health Alliance, NARAL, so many organizations, including the National Alliance for Mental Illness, the Community Behavioral Healthcare Association, and the March of Dimes. I want to thank these individuals and various activists for their testimony at hearings, for their support, and for their participation.

Madam Speaker, lastly, I want to thank the Members of this Congress, those who, when I asked to become cosponsors, they indicated that they were familiar because they had personal involvement, this dreaded disease has touched them personally; and I want to thank them for their support.

Madam Speaker, I urge that this body pass this much-needed legislation, that this body, indeed, give women the help that they need in fighting this very, very difficult disease.

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

Ms. BALDWIN. Madam Speaker, in closing, I wish to urge my colleagues to support this important bill. As we have heard, postpartum depression is a very serious women's health issue. This bill will raise awareness about postpartum depression and will further research in an effort to find a cure.

☐ 1615

Again I want to commend my colleague (Mr. RUSH) for his incredibly hard work on this bill, and I urge my colleagues to support its passage.

Ms. RICHARDSON. Madam Speaker, I rise today to support H.R. 20, the Melanie Blocker-Stokes Postpartum Depression Research and Care Act.

Postpartum depression is a serious mental health problem that can have significant consequences for both the new mother and family. Statistics show up to 800,000 women annually develop this diagnosable prenatal mood disorder; shockingly, less than 15 percent of mothers will receive treatment for the disease.

In California, the results from a 2004 California Women's Health 2007 study indicated that younger females were most at risk for postpartum depression. Females 19 and younger had rates of risk of more than 20 percent: woman 35 and older had the lowest rate, 6.4 percent. In California, woman who are young and/or without health insurance would benefit most from the screening, counseling, diagnosis, and treatment for postpartum depression that this legislation authorizes.

H.R. 20, the Melanie Blocker-Stokes Postpartum Depression Research and Care Act, would ensure that woman at risk for or with postpartum depression are provided adequate and timely prevention and mental health services.

If we are to have any hope of preventing deaths among new mothers and children from this disease, we must identify ways by which we can effectively treat and prevent postpartum psychosis.

I extend my gratitude and thanks to Representative RUSH for bringing this important piece of legislation to the House. His commitment to this issue is commendable.

Ms. BALDWIN. Madam Speaker, I yield back the remainder of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentlewoman from Wisconsin (Ms. BALDWIN) that the House suspend the rules and pass the bill, H.R. 20, as amended.

The question was taken.

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

Ms. BALDWIN. Madam Speaker, on that I demand the yeas and nays.

The yeas and nays were ordered.

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.

ALS REGISTRY ACT

Ms. BALDWIN. Madam Speaker, I move to suspend the rules and pass the bill (H.R. 2295) to amend the Public Health Service Act to provide for the establishment of an Amyotrophic Lateral Sclerosis Registry, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 2295

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. FINDINGS.

Congress makes the following findings:

(1) Amyotrophic lateral sclerosis (referred to in this section as ''ALS'') is a fatal, progressive neurodegenerative disease that affects motor nerve cells in the brain and the spinal cord.

(2) The average life expectancy for a person with ALS is 2 to 5 years from the time of diagnosis.

(3) The cause of ALS is not well understood.

(4) There is only one drug currently approved by the Food and Drug Administration for the treatment of ALS, which has thus far shown only modest effects, prolonging life by just a few months.

(5) There is no known cure for ALS.

(6) More than 5,000 individuals in the United States are diagnosed with ALS annually and as many as 30,000 individuals may be living with ALS in the United States today.

(7) Studies have found relationships between ALS and environmental and genetic factors, but those relationships are not well understood.

(8) Scientists believe that there are significant ties between ALS and other motor neuron diseases.

(9) Several ALS disease registries and databases exist in the United States and throughout the world, including the SOD1 database, the National Institute of Neurological Disorders and Stroke repository, and the Department of Veterans Affairs ALS Registry.

(10) A single national system to collect and store information on the prevalence and incidence of ALS in the United States does not exist.

(11) In each of fiscal years 2006 and 2007, Congress directed $887,000 to the Centers for Disease Control and Prevention to begin a nationwide ALS registry.

(12) The Centers for Disease Control and Prevention and the Agency for Toxic Substances and Disease Registry have established three pilot projects, beginning in fiscal year 2006, to evaluate the science to guide the creation of a national ALS registry.

(13) The establishment of a national registry will help—

(A) to identify the incidence and prevalence of ALS in the United States;

(B) to collect data important to the study of ALS;

(C) to promote a better understanding of ALS;

(D) to collect information that is important for research into the genetic and environmental factors that cause ALS;

(E) to strengthen the ability of a clearinghouse—

(i) to collect and disseminate research findings on environmental, genetic, and other causes of ALS and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS;

(ii) to make available information to patients about research studies for which they may be eligible; and

(iii) to maintain information about clinical specialists and clinical trials on therapies; and

(F) to enhance efforts to find treatments and a cure for ALS.

SEC. 3. 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)(3), the Secretary, acting through the Director of the Centers for Disease Control and Prevention and in consultation with a national voluntary health organization with experience serving the population of individuals with amyotrophic lateral sclerosis (referred to in this section as 'ALS'), shall—

''(A) develop a system to collect data on 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 include 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 gather available data concerning—

''(A) ALS, including the incidence and prevalence of ALS in the United States;

''(B) the environmental and occupational factors that may be associated with the disease;

''(C) the age, race or ethnicity, gender, and family history of individuals who are diagnosed with the disease;

''(D) 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 90 days after the date of the enactment of this section, the Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall 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 at least one member, to be appointed by the Secretary, acting through the Director of the Centers for Disease Control and Prevention, representing each of the following:

''(A) National voluntary health associations that focus solely on ALS and have demonstrated experience in ALS research, care, and patient services, as well as other voluntary associations focusing on neurodegenerative diseases that represent and advocate on behalf of patients with ALS and patients with other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS.

''(B) 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.

''(C) The Department of Veterans Affairs.

''(D) The Agency for Toxic Substances and Disease Registry.

''(E) The Centers for Disease Control and Prevention.

''(F) Patients with ALS or their family members.

''(G) Clinicians with expertise on ALS and related diseases.

''(H) Epidemiologists with experience in data registries.

''(I) Geneticists or experts in genetics who have experience with the genetics of ALS or other neurological diseases.

''(J) Statisticians.

''(K) Ethicists.

''(L) Attorneys.

''(M) Other individuals with an interest in developing and maintaining the National ALS Registry.

''(2) DUTIES.—The Advisory Committee shall 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 1 year after the date on which the Advisory Committee is established, the Advisory Committee shall submit a report 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.—Notwithstanding the recommendations of the Advisory Committee under subsection (b), 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.

''(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, shall—

''(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, including—

''(i) the 3 ALS registry pilot projects initiated in fiscal year 2006 by the Centers for Disease Control and Prevention and the Agency for Toxic Substances and Disease Registry at the South Carolina Office of Research & Statistics; the Mayo Clinic in Rochester, Minnesota; and Emory University in Atlanta, Georgia;

''(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;

''(iv) the 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, including the Massachusetts ALS Registry;

''(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.—Notwithstanding the recommendations of the Advisory Committee established in subsection (b), and consistent with applicable privacy statutes and regulations, the Secretary shall 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.

''(f) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section, $25,000,000 for fiscal year 2008, and $16,000,000 for each of the fiscal years 2009 through 2012.''.

The SPEAKER pro tempore. Pursuant to the rule, the gentlewoman from Wisconsin (Ms. BALDWIN) and the gentleman from New York (Mr. FOSSELLA) each will control 20 minutes.

The Chair recognizes the gentlewoman from Wisconsin.

GENERAL LEAVE

Ms. BALDWIN. Madam Speaker, I ask unanimous consent that all Members have 5 legislative days 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 gentlewoman from Wisconsin?

There was no objection.

Ms. BALDWIN. Madam Speaker, I yield myself such time as I might consume.

Madam Speaker, I rise in support of H.R. 2295 the ALS Registry Act. Amyotrophic lateral sclerosis, or 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 the 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 toward better understanding ALS, and to develop measures for prevention, treatment and cure of this dreaded disease.

Madam Speaker, I would like to thank my friend and colleague, Representative ELIOT ENGEL, for his dedication to bringing this bill before us today. Madam Speaker, I strongly urge my colleagues to support H.R. 2295.

I reserve the balance of my time.

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

Madam Speaker, I would also like to thank Congressman ENGEL and Congressman TERRY for their efforts in the establishment of the ALS Registry Act. As we know, we have an annual event here in Congress when we get visits from members of the ALS organization, the association, and their advocates, but more importantly the citizens of this country who have been afflicted with Lou Gehrig's disease. It is gut-wrenching to watch knowing full well what a debilitating disease it is, and it knows no boundaries. As has been mentioned by my colleagues, perhaps 30,000 Americans, perhaps 1,000 in New York State alone, are suffering with ALS. I know a gentleman on Staten Island who helped to have built one of the largest banks in Staten Island, if not the largest, retiring, thinking he was going to enjoy his golden years, and soon after that became diagnosed with ALS. To watch the horrific progression over the last couple of years is, as I mentioned, gut-wrenching not just to his friends but, I am sure, his family.

That is why I think it is important that Congress finally step up and act, and as a cosponsor of the legislation today, I am pleased to see it brought to the House floor today.

I would like to thank the tireless efforts of the ALS Association and advocates in educating and advocating for a cure, which is what we all want. Unfortunately, we know little about ALS, a disease that is diagnosed for 5,600 Americans each year. Without a cure and without treatments to slow the progression of the disease, as has been mentioned by Ms. BALDWIN, the average life expectancy of a person is only 2 to 5 years. It is a death sentence once diagnosed. The rapid progression, lack of understanding about its cause, and debilitating nature of the disease make it particularly hard on those afflicted with ALS, as well as their family and friends.

We need to give scientists the tools they need to find the treatment and cure for ALS. The registry does just that. It creates a single, national patient registry to collect and store information on the prevalence of incidences of ALS in the U.S. We know of several research studies ongoing at the NIH and other private facilities, investigating possible risk factors that may be associated with ALS. Researchers are working to better determine what genetics and/or environmental factors are contributing to developing ALS.

While there has been incredible and groundbreaking advances in science that give hope to people with Lou Gehrig's disease and their families, this legislation will provide an important new link that will allow scientists to take emerging new discoveries ever closer to a cure. And I pray that one day we will have that cure so no families or individuals will be afflicted by this terrible disease.

Madam Speaker, I stand in support, urge adoption and reserve the balance of my time.

Ms. BALDWIN. Madam Speaker, I yield 4 minutes to the bill's author, the distinguished gentleman from New York (Mr. ENGEL).

Mr. ENGEL. Madam Speaker, I thank the gentlewoman from Wisconsin for yielding to me.

Madam Speaker, I wish to thank you for bringing up the ALS Registry Act of 2007 for a vote, H.R. 2295. This is truly a bipartisan measure, as well it should be. I introduced this bill with my colleague, LEE TERRY of Nebraska, and we are proud to have the support of over 275 bipartisan members of Congress.

I know that the gentlewoman from Wisconsin who sat next to me on the committee was very concerned about this bill. I am glad that the gentleman from New York (Mr. FOSSELLA) is here, as well, because I have a picture here of Lou Gehrig who, of course, puts a face on this disease. ALS is very often known as Lou Gehrig's disease, and we all remember the Yankee Clipper, Lou Gehrig. Mr. FOSSELLA and I, both coming from New York, we know Lou Gehrig and his tradition very, very well.

Amyotrophic lateral sclerosis, or ALS, is a fatal, progressive neurodegenerative disease that affects motor nerve cells in the brain and spinal cord. It is very similar to multiple sclerosis. While the great baseball player, Lou Gehrig, put a national face on ALS over 65 years ago, my own family was devastated by the death of my grandmother, Dora Engel, my father's mother, who is believed to have passed away as a result of ALS when she was about 58 years old.

Unfortunately, families across the Nation face challenges and experience the suffering associated with ALS every single day. As was mentioned before, 5,600 people in the U.S. are diagnosed with ALS each year. It is estimated that as many as 30,000 Americans have the disease at any given time. The average life expectancy for a person who is diagnosed with ALS is only 2 to 5 years from the time of diagnosis.

As was mentioned, the causes of ALS are not well understood and there is no known cure. We need to provide hope to change this tragedy today.

Surprisingly, a single national patient registry which collects and stores information on the prevalence and incidence of ALS does not currently exist in the United States today. The legislation I introduced with my colleague (Mr. TERRY) would create an ALS registry at the Centers for Disease Control and Prevention and aid in the search for a cure from this devastating disease. The registry would collect key data, and information is determined by a newly created Federal Advisory Committee on the National ALS Registry.

The ALS Registry Act will also build upon a fiscal year 2006 and fiscal year 2007 congressional appropriation which directed the CDC to evaluate the science to guide the creation of a National ALS Registry.

I wish to express my gratitude to the staff of the Centers for Disease Control and Prevention, and in particular to the ALS Association, who worked for months with me and my staff to improve the bill that we had introduced in the previous 109th Congress. I also want to thank Chairman DINGELL, Ranking Member BARTON, House Subcommittee Chairman PALLONE and Ranking Member DEAL for their support of the ALS Registry Act. Finally, I especially want to thank John Ford and William Garner of Chairman DINGELL's staff and Katherine Martin of Ranking Member BARTON's staff for shepherding this bill through the Energy and Commerce Committee. I want to thank Emily Gibbons of my own staff, my legislative director, who was also my health expert and really did more for this than anybody else I know.

The establishment of a registry will bring new hope to thousands of patients and their families that ALS will no longer be a death sentence. I thank my colleagues, and Madam Speaker, I urge the swift passage of the ALS Registry Act, H.R. 2295, today.

Mr. FOSSELLA. I reserve the balance of my time.

Ms. BALDWIN. Madam Speaker, I yield 1½ minutes to the gentlewoman from South Dakota, Congresswoman HERSETH SANDLIN.

Ms. HERSETH SANDLIN. Madam Speaker, I rise in support of H.R. 2295, the ALS Registry Act, introduced by the gentleman from New York (Mr. ENGEL). I would like to thank my friend and colleague from Wisconsin (Ms. BALDWIN) for yielding me time.

No one who knows or has met someone diagnosed with ALS can fail to be moved by the courage, not only of those experiencing the symptoms of this disease, but of their family, who help them cope with it every day.

During the National ALS Awareness Month in May, I met with one such remarkable family. Daryl and Marlene Thorson of Brandon, South Dakota, and their granddaughter, Elizabeth Steel, took the time to visit with me. They discussed the importance of this legislation to create a National ALS Registry, and they talked about living with ALS. Daryl has been diagnosed with ALS, and his wife is a pillar of strength as they go through this together. Their love was clear, as was their determination. I was struck by their 12-year-old granddaughter, Elizabeth, who sees how the disease has affected her grandfather and sees her grandmother caring for him. Elizabeth wrote an essay for school entitled, ''If I Had a Million Dollars, What Would I Buy?'' And Elizabeth dedicated her entire essay to buying supplies for her grandfather, funding research, and advocating to Members of Congress.

Madam Speaker, by establishing a National ALS Registry and providing the requisite funding, we can help facilitate the efforts of so many across the country, like Elizabeth, like the scientists searching for a cure, who are working to conquer ALS and bring comfort to those afflicted with it. I urge my colleagues to support this important legislation.

Mr. FOSSELLA. Madam Speaker, I am told that my colleague has no further speakers, so I would close. And as I mentioned, I have been here now 10 years. I can recall a gentleman by the name of Gary Anderson coming up after being diagnosed, a friend from Staten Island, and passing after suffering for too long from ALS. It is a terrible indictment, Lou Gehrig's disease, that it is, and one day, as we say, perhaps this registry will get to a point where no longer will our fellow citizens have to suffer. So, for people like Gary Anderson, to this day, a gentleman I mentioned before, Harry Doherty, who is currently suffering as we speak, I would urge the adoption of this.

I yield back the balance of my time.

Ms. BALDWIN. Madam Speaker, in closing, I strongly support this bill. As we have heard, this bill would collect data which is urgently needed for ALS research and will go a long way toward moving us closer to treatments and a cure for this devastating illness.

Again, I wish to recognize my colleague (Mr. ENGEL) and other colleagues who have spoken today who put a personal face and a personal story behind this important legislation.

Madam Speaker, I urge my colleagues to support this bill.

Mr. TERRY. Madam Speaker, I rise today in strong support of The ALS Registry Act of 2007, originally introduced in May by my colleague Representative ELIOT ENGEL of New York and myself. As the bill comes to the floor, we have been joined by 275 bipartisan cosponsors in support of this important legislation.

Amyotrophic Lateral Sclerosis (ALS) is a fatal, progressive, neurodegenerative disease affecting motor nerve cells in the brain and spinal cord. Approximately 5,600 people in the U.S. are diagnosed with ALS, also known as Lou Gehrig's Disease, each year. It is estimated that as many as 30,000 Americans have the disease. The average life expectancy for a person with ALS is two to five years from the time of diagnosis. There is no known cure for ALS.

The most important provision in our bill establishes a national ALS registry. There is currently no single national registry which collects and stores information on the prevalence and incidence of ALS in existence in the United States. The establishment of a national registry will help identify the occurrence and frequency of ALS and other motor neuron disorders and collect data which is badly 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.

A recent article from the New England Journal of Medicine stated that "approximately 90 percent of the persons with ALS have the sporadic form, which may be caused by the interaction of multiple environmental factors and previously unknown genes." The purpose of creating a registry is to identify if there are any geographic, genetic or environmental groups of people that have been diagnosed with this terrible disease. This would then allow scientists a better opportunity to identify any relevant factors. This registry may sound simple on the surface, but it is actually a significant tool in determining the root causes of ALS, which would hopefully lead to diagnostic tests and screenings to see who is susceptible to the disease.

Although we know the debilitating effects of ALS, I am moved every year when I am visited by patients and their families in my Washington office. Despite the extremely challenging medical conditions faced by these patients, they make an extraordinary effort to travel to the Capitol and share their stories in the hope that we will soon find effective treatments and a potential cure so that no one like them will have to suffer in the future. The courage shown by ALS patients, as well as their families, is inspiring to me.

All diseases bring hardships on those afflicted, but ALS is particularly cruel in the quickness of the onset, the severity of the symptoms and the fatal nature of the condition. The provisions in our bill creating a nationwide registry for persons afflicted with ALS are important steps forward in strengthening the efforts to understand, treat and one day eradicate this terrible disease. I urge my colleagues to support the ALS Registry Act and I am proud to have worked on this very important effort with my friend Mr. ENGEL. I am also grateful that our committee, the Energy and Commerce Committee, took up this legislation and advanced the bill to the floor.

Mr. PATRICK J. MURPHY of Pennsylvania. Madam Speaker, I rise today in support of H.R. 2295, to amend the Public Health Service Act to provide for the establishment of an Amyotrophic Lateral Sclerosis Registry.

ALS, more commonly known as Lou Gehrig's disease, is a particularly cruel disease and is always fatal, usually between two and five years after diagnosis. One of the very few trends researchers have been able to identify is that veterans are twice as likely to die from ALS as those who have not served in the military. However, Madam Speaker, it can strike at any time, regardless of age, race, gender or nationality.

This fight is personal for me, as my good friend Shelbie Oppenheimer, and her husband Jeff have long been advocates for those with ALS.

Shelbie was diagnosed when she was just 28 years old and has since spent countless hours educating friends, family, community members and elected officials. Shelbie has been fortunate—still fighting after 10 years.

The Oppenheimers have created a wonderful organization based in my district in Bucks County, Pennsylvania: Shelbie.org.

Along with many community partners, they work tirelessly to provide opportunities for the children of ALS patients. Jeff and Shelbie, along with their daughter Isabel, are a constant inspiration to me and I join them in the fight to turn ALS from a disease to a memory.

It is for Shelbie, Jeff, Isabel and countless others that I am proud to be a cosponsor of this bill. This legislation will create, through the Centers for Disease Control and Prevention, a single, nationwide ALS registry. This Registry is essential to advancing the search for treatments and the cure.

Since we don't know the cause or the cure of ALS, research is the key. Enabling researchers, doctors and patients to understand the trends and history of the disease is vital to moving forward. The Registry will gather data on the environmental and occupational factors that may contribute to the disease, including the age, race and ethnicity of individuals with ALS, the patients' family histories and other information that may be beneficial to advancing research and care.

Madam Speaker, I urge all of my colleagues to join this fight and support the ALS Registry Act and vote yes on H.R. 2295.

Mr. SHAYS. Madam Speaker, I am an original cosponsor of H.R. 2295, the ALS Registry Act. The legislation would direct the Centers for Disease Control and Prevention to develop a system to collect data on ALS and establish a national registry for the collection and storage of this data.

Creating the registry will allow us to better understand the incidence and prevalence of the disease, the age, race and ethnicity of people who have it, and whether there are any environmental factors that are associated with the disease.

ALS, commonly known as Lou Gehrig's Disease, is a progressive neuromuscular disease characterized by a degeneration of the nerve cells of the brain and spinal cord leading to the wasting of muscles, paralysis and eventual death. Approximately 30,000 individuals in the United States are afflicted with ALS, with approximately 5,000 new cases each year.

The life expectancy of an individual with ALS is 3 to 5 years from the time of diagnosis. While there is no known cure or cause for ALS, aggressive treatment of the symptoms of ALS can extend the lives of those with the disease. Promising research gives hope that one day this deadly and debilitating disease will be cured.

Ms. BALDWIN. I yield back the remainder of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentlewoman from Wisconsin (Ms. BALDWIN) that the House suspend the rules and pass the bill, H.R. 2295, as amended.

The question was taken.

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

Ms. BALDWIN. Madam Speaker, on that I demand the yeas and nays.

The yeas and nays were ordered.

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.

□ 1630

CHRISTOPHER AND DANA REEVE PARALYSIS ACT

Ms. BALDWIN. Madam Speaker, I move to suspend the rules and pass the bill (H.R. 1727) to enhance and further research into paralysis and to improve rehabilitation and the quality of life for persons living with paralysis and other physical disabilities, and for other purposes, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 1727

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 "Christopher and Dana Reeve Paralysis Act".

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TITLE III—IMPROVING QUALITY OF LIFE FOR PERSONS WITH PARALYSIS AND OTHER PHYSICAL DISABILITIES

Sec. 301. Programs to improve quality of life for persons with paralysis and other physical disabilities.