

out that will be approved on the House floor. That is a pretty good record of achievement.

This one really, like the others, has a real impact on all of our constituents. It gives the FDA the rightful tools, so that we can get to the bottom of the problem which impacts one in 50 Americans.

So, again, I want to compliment Mr. DINGELL, Mr. WHITFIELD, Mr. PALLONE, Mr. WAXMAN, and others for helping deliver this bill to the House floor, and I look forward to a strong vote—hopefully voice—in a few minutes.

Mr. DINGELL. Mr. Speaker, I have no further requests for time, so if the gentleman, my good friend, Mr. WHITFIELD, is ready, I am prepared to yield back with the strong urging to my colleagues to support this bill—which is strongly bipartisan—unanimously brought forward to the Congress and which has the strong support of both industry, government, and health groups.

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

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

Mr. Speaker, I want to, once again, thank Mr. DINGELL, and I appreciate his naming the staff because there was a lot of negotiations with FDA on this bill, and Taylor Booth on my staff and other members of the Energy and Commerce Committee staff, as named by Mr. DINGELL, I want to give special thanks to them, and also, we appreciate the efforts of Mr. PITTS, who is the chairman of the Health Subcommittee.

Without the help of him, Mr. PALLONE, and their staffs, we would not have been able to bring this bill to the floor. So I would urge everyone to support it, and with that, I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from Kentucky (Mr. WHITFIELD) that the House suspend the rules and pass the bill, H.R. 4250, 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.

PAUL D. WELLSTONE MUSCULAR DYSTROPHY COMMUNITY ASSISTANCE, RESEARCH AND EDUCATION AMENDMENTS OF 2014

Mr. BURGESS. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 594) to reauthorize and extend the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2008, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 594

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 “Paul D. Wellstone Muscular Dystrophy Community Assistance, Research and Education Amendments of 2014”.

SEC. 2. INITIATIVE THROUGH THE DIRECTOR OF THE NATIONAL INSTITUTES OF HEALTH.

Section 404E of the Public Health Service Act (42 U.S.C. 283g) is amended—

(1) in subsection (a)(1)—
(A) by striking “Musculoskeletal” and inserting “Musculoskeletal”; and

(B) by inserting “Becker, congenital muscular dystrophy, limb-girdle muscular dystrophy,” after “Duchenne,”;

(2) in subsection (b)—
(A) in paragraph (2)—

(i) by striking “genetics,” at the second place it appears; and

(ii) by inserting “cardiac and pulmonary function, and” after “imaging,”; and

(B) in paragraph (3), by inserting “and sharing of data” after “regular communication”;

(3) in subsection (d)—
(A) in paragraph (2)—

(i) in the matter preceding subparagraph (A), by striking “15” and inserting “18”; and

(ii) in subparagraph (A)—

(I) by striking “and the Food and Drug Administration” and inserting “, the Food and Drug Administration, and the Administration for Community Living”;

(II) by inserting “and adults” after “children”; and

(III) by striking “such as the Department of Education” and inserting “including the Department of Education and the Social Security Administration”; and

(B) in paragraph (4)(B), by inserting “, but shall meet no fewer than two times per calendar year” before the period; and

(4) in subsection (e)—
(A) in paragraph (1)—

(i) in the matter preceding subparagraph (A), by striking “through the national research institutes” and inserting “through the agencies represented on the Coordinating Committee pursuant to subsection (d)(2)(A)”; and

(ii) in subparagraph (A)—
(I) by inserting “public services,” before “and rehabilitative issues”; and

(II) by inserting “, studies to demonstrate the cost-effectiveness of providing independent living resources and support to patients with various forms of muscular dystrophy, and studies to determine optimal clinical care interventions for adults with various forms of muscular dystrophy” after “including studies of the impact of such diseases in rural and underserved communities”; and

(B) in paragraph (2)(D), by inserting after “including new biological agents” the following: “and new clinical interventions to improve the health of those with muscular dystrophy”.

SEC. 3. SURVEILLANCE AND RESEARCH REGARDING MUSCULAR DYSTROPHY.

The second sentence of section 317Q(b) of the Public Health Service Act (42 U.S.C. 247b-18(b)) is amended by inserting before the period the following: “and, to the extent possible, ensure that data be representative of all affected populations and shared in a timely manner”.

SEC. 4. INFORMATION AND EDUCATION.

Section 5(c) of the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (42 U.S.C. 247b-19(c)) is amended—

(1) in paragraph (2)—
(A) by inserting “for pediatric and adult patients, including acute care considerations,” after “issuance of care considerations”;

(B) by inserting “various” before “other forms of muscular dystrophy”; and

(C) by striking “and” at the end;

(2) by redesignating paragraph (3) as paragraph (4);

(3) by inserting after paragraph (2) the following:

“(3) in developing and updating care considerations under paragraph (2), incorporate strategies specifically responding to the findings of the national transitions survey of minority, young adult, and adult communities of muscular dystrophy patients; and”;

(4) in paragraph (4), as redesignated, by inserting “various” before “other forms of muscular dystrophy”.

The SPEAKER pro tempore. Pursuant to the rule, the gentleman from Texas (Mr. BURGESS) and the gentleman from New York (Mr. ENGEL) each will control 20 minutes.

The Chair recognizes the gentleman from New York.

GENERAL LEAVE

Mr. BURGESS. Mr. Speaker, I ask unanimous consent that all Members may have 5 legislative days in which to revise and extend their remarks and insert extraneous materials in the RECORD on the bill.

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

There was no objection.

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

Mr. Speaker, thank you for the recognition to discuss this bipartisan, bicameral legislation that was introduced with Mr. ENGEL of New York, H.R. 594, the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2014, or the MD CARE Act.

H.R. 594 has 113 bipartisan cosponsors. This bill makes targeted updates and improvements to legislation first passed by Congress in 2001 and then reauthorized in 2008. In each instance, these bills, including H.R. 594, have passed both subcommittee and full committee on voice votes and passed overwhelmingly on the floor under suspension, a trend I hope we can continue today.

Mr. Speaker, this legislation is supported by the totality of the muscular dystrophy community with over 20 organizations writing letters of support, including the Muscular Dystrophy Association and the Parent Project Muscular Dystrophy.

In short, the underlying law is a success story. Since its enactment, this law has successfully targeted limited Federal resources to improve clinical care across the muscular dystrophies.

Muscular dystrophy is not a single disease. It is a group of genetic disorders characterized by progressive weakness and the loss of voluntary muscles that control movement.

Muscular dystrophy affects hundreds of thousands of children and adults throughout the United States and worldwide. Some forms of muscular dystrophy are seen in infancy or childhood, while others may not appear until adulthood. The extent of muscle weakness, as well as rate of progression, varies based on where among a spectrum of muscular dystrophies a patient falls.

Since 2001, this law has successfully changed the lives of families impacted

by all forms of muscular dystrophy. It has coordinated and focused Federal biomedical research on nine forms of muscular dystrophy, developed epidemiologic data, and created patient care guidelines.

Here is the good news: it has made a real difference. Since 2001, there have been 67 clinical trials of drugs or therapies for muscular dystrophy, and many can be traced to the basic research efforts stemming from this law.

In Duchenne muscular dystrophy alone, children are living 10 years longer, and many are now entering young adulthood. However, as we often heard, sometimes the law does not keep pace with science and medicine.

For example, when the original law was written, those children who are now going into adulthood would not have been able to look forward to such a favorable timeline. It does not make sense that we have developed care guidelines that have helped these patients live longer and then stop when they turn 18. This bill will address these issues with small, targeted updates to current law.

Mr. Speaker, let me be very clear about this. This bill creates no new programs, this bill creates no increases of authorizations of appropriations, nor does it create additional authorizations of appropriations. It simply proposes a small set of improvements intended to ensure that the program is focusing on the most critical areas that funding being provided today reflects current scientific and medical knowledge.

The bill is fiscally responsible because it makes the needed update in law to ensure that any money that is spent is not held back by an outdated statute.

I would like to thank Chairmen UPTON and PITTS, as well as Ranking Members WAXMAN and PALLONE for their help. I also want to thank the staff on both sides of the dais in the committee and the Capitol for their work in getting this bill to this point.

Specifically, I want to thank Clay Alspach, Katie Novaria, and Brenda Destro with the Energy and Commerce majority, and Hannah Green with the minority; from Mr. ENGEL's staff, Mark Iozzi and Heidi Ross, who negotiated with my staff in good faith from day one; and on my staff, I particularly want to thank my deputy chief of staff J.P. Paluskiewicz who led negotiations, as well as Katie Allen and my former staffer, Sarah Johnson.

This bill is bipartisan. It has a history of consensus. It is fiscally responsible and will benefit all Americans suffering from muscular dystrophy.

I urge everyone to support it, and I reserve the balance of my time.

Mr. ENGEL. Mr. Speaker, I rise in strong support of H.R. 594, the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research and Education Amendments, and I yield myself such time as I may consume.

Mr. Speaker, I worked with the gentleman from Texas, Dr. BURGESS, to in-

troduce this bill, and I would personally like to thank him for his hard work and partnership developing the legislation and bringing it through the Energy and Commerce Committee.

I would also like to thank our colleagues, Representatives WAXMAN, PALLONE, PITTS, and UPTON, for their support and effort to get this bill here today.

Mr. Speaker, the MD CARE Act has always enjoyed full bipartisan support. Congress first approved it in 2001, we updated it in 2008, and we are doing the same now. I am pleased to see that this bipartisan tradition remains strong as we continue the fight against muscular dystrophy by taking up this legislation today.

As I am sure many of my colleagues already know and as Dr. BURGESS pointed out, muscular dystrophy is not a single disease, but a spectrum of genetic disorders resulting from progressive muscle weakness and degeneration.

Hundreds of thousands of children and adults currently suffer from various forms of muscular dystrophy in the United States and around the world.

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Although there is still no cure, the MD CARE Act has played a critical role in improving the lives of those suffering from these lethal disorders. The MD CARE Act has successfully coordinated and focused biomedical research, established clinical care standards, improved data collection, and helped generate more than 65 clinical trials, more than 30 of which are still ongoing.

As a direct result of this law, the lifespan of the average American living with Duchenne muscular dystrophy—the most common form of muscular dystrophy in children—has increased by a full 10 years. That is a statistic of which we can be proud. This progress is substantial, and the law needs to be updated to reflect these developments.

As people live longer, their needs evolve. The legislation we are considering today responds to the changing needs of muscular dystrophy patients without requiring any additional authorization of appropriations. It will make targeted updates to the MD CARE Act, bringing our programs in line with the scientific advancements we have made since 2008 when the law was last updated.

The bill allows the Director of the National Institutes of Health to expand and intensify programs targeted at the nine most common forms of muscular dystrophy. It also enhances research at the Wellstone Centers of Excellence, strengthens the Muscular Dystrophy Coordinating Committee, updates data collection, and increases awareness of treatment options among medical professionals.

This bill is supported by 113 bipartisan cosponsors, and it has the full backing of the muscular dystrophy community. Passing H.R. 594 will make

a huge difference in the lives of all those affected by muscular dystrophy. I urge my colleagues to give it their full support.

I want to conclude by thanking majority and minority staff, which Dr. BURGESS mentioned, and I once again thank him for his partnership on this bill.

I yield back the balance of my time.

Mr. BURGESS. Mr. Speaker, I yield 5 minutes to the gentleman from Michigan (Mr. UPTON), chairman of the full committee.

Mr. UPTON. Mr. Speaker, I rise this afternoon in support of yet another very important health bill advanced by our Energy and Commerce Committee, H.R. 594, the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research and Education Amendments of 2014, or the MD CARE Act. The bill again demonstrates the continued bipartisan achievements of our committee, and particularly of the Health Subcommittee which has a proven track record of getting solutions put into law that have a profound, positive effect on Americans all across the country.

Muscular dystrophy, it is a complex group of diseases that affects the mobility and life expectancy of so many Americans. Current treatments can alleviate symptoms of the muscular dystrophies like Duchenne and slow muscle deterioration, but there is no treatment to reverse it. It is very sad. Even with the progress made by researchers, obviously a lot of work remains.

This legislation is going to help us find the answers to these diseases. The bill ensures the continuation of critical research at the NIH and updates language in the Public Health Service Act to reflect the latest scientific advances. In addition, the Muscular Dystrophy Coordinating Committee of HHS is going to be strengthened to accelerate the understanding of the impact of muscular dystrophy on patients; and, more importantly, it is going to work to find ways to expedite the approval of emerging therapies that will hopefully some day lead to a cure.

I want to particularly thank Dr. BURGESS and ELIOT ENGEL for their leadership on this bill, and also Chairman PITTS and Ranking Members WAXMAN and PALLONE.

I have to say that this is now the 62nd bill that our committee will have passed out of full committee that will pass on the House floor. We have more than a dozen bipartisan committee bills, public health bills that have already been signed into law. We hope this will be one of those as we advance this bill, as well as the Sunscreen Innovation Act, which we just passed a few minutes ago.

I know that this Congress can be remembered as the public health Congress, and I urge my colleagues to support this important legislation which passed by a voice vote unanimously in our committee. It sends a strong signal

to those individuals and their families impacted by muscular dystrophy that Congress—yes, we are—is committed to finding a cure. We will find the resources to do this. This legislation is yet another step, and I urge my colleagues to vote “yes.”

Mr. BURGESS. Mr. Speaker, let me close by saying this is a good bill, and I urge all Members to support it.

I yield back the balance of my time.

Mr. WAXMAN. Mr. Speaker, I want to express my support for H.R. 594, the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research and Education (MD CARE) Amendments of 2014.

The Centers for Disease Control and Prevention and the National Institutes of Health oversee a number of research, surveillance, and educational efforts involving muscular dystrophy.

H.R. 594 will build upon the federal government's current activities regarding muscular dystrophy. Scientific advances have extended the lives of individuals living with forms of muscular dystrophy—like Duchenne. Today's legislation will help better incorporate the needs of adults with muscular dystrophy into current work in this area.

Congressman ENGEL and Congressman BURGESS should be recognized for their leadership on this issue. I would also like to thank Chairman UPTON, Chairman PITTS, Ranking Member PALLONE, and all of our staff for their work in advancing this bill through the Energy and Commerce Committee.

I support H.R. 594 and urge my colleagues to do the same.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from Texas (Mr. BURGESS) that the House suspend the rules and pass the bill, H.R. 594, as amended.

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

The title of the bill was amended so as to read: “A bill to amend the Public Health Service Act relating to Federal research on muscular dystrophy, and other purposes.”

A motion to reconsider was laid on the table.

SAFE AND SECURE FEDERAL WEBSITES ACT OF 2014

Mr. BENTIVOLIO. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 3635) to ensure the functionality and security of new Federal websites that collect personally identifiable information, and for other purposes, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 3635

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 “Safe and Secure Federal Websites Act of 2014”.

SEC. 2. ENSURING FUNCTIONALITY AND SECURITY OF NEW FEDERAL WEBSITES THAT COLLECT PERSONALLY IDENTIFIABLE INFORMATION.

(a) CERTIFICATION REQUIREMENT.—

(1) IN GENERAL.—Except as otherwise provided under this subsection, an agency may not deploy or make available to the public a new Federal PII website until the date on which the chief information officer of the agency submits a certification to Congress that the website is fully functional and secure.

(2) TRANSITION.—In the case of a new Federal PII website that is operational on the date of the enactment of this Act, paragraph (1) shall not apply until the end of the 90-day period beginning on such date of enactment. If the certification required under paragraph (1) for such website has not been submitted to Congress before the end of such period, the head of the responsible agency shall render the website inaccessible to the public until such certification is submitted to Congress.

(3) EXCEPTION FOR BETA WEBSITE WITH EXPLICIT PERMISSION.—Paragraph (1) shall not apply to a website (or portion thereof) that is in a development or testing phase, if the following conditions are met:

(A) A member of the public may access PII-related portions of the website only after executing an agreement that acknowledges the risks involved.

(B) No agency compelled, enjoined, or otherwise provided incentives for such a member to access the website for such purposes.

(4) CONSTRUCTION.—Nothing in this section shall be construed as applying to a website that is operated entirely by an entity (such as a State or locality) that is independent of the Federal Government, regardless of the receipt of funding in support of such website from the Federal Government.

(b) DEFINITIONS.—In this section:

(1) AGENCY.—The term “agency” has the meaning given that term under section 551 of title 5, United States Code.

(2) FULLY FUNCTIONAL.—The term “fully functional” means, with respect to a new Federal PII website, that the website can fully support the activities for which it is designed or intended with regard to the eliciting, collection, storage, or maintenance of personally identifiable information, including handling a volume of queries relating to such information commensurate with the purpose for which the website is designed.

(3) NEW FEDERAL PERSONALLY IDENTIFIABLE INFORMATION WEBSITE (NEW FEDERAL PII WEBSITE).—The terms “new Federal personally identifiable information website” and “new Federal PII website” mean a website that—

(A) is operated by (or under a contract with) an agency;

(B) elicits, collects, stores, or maintains personally identifiable information of individuals and is accessible to the public; and

(C) is first made accessible to the public and collects or stores personally identifiable information of individuals, on or after October 1, 2012.

(4) OPERATIONAL.—The term “operational” means, with respect to a website, that such website elicits, collects, stores, or maintains personally identifiable information of members of the public and is accessible to the public.

(5) PERSONALLY IDENTIFIABLE INFORMATION (PII).—The terms “personally identifiable information” and “PII” mean any information about an individual elicited, collected, stored, or maintained by an agency, including—

(A) any information that can be used to distinguish or trace the identity of an individual, such as a name, a social security number, a date and place of birth, a mother's maiden name, or biometric records; and

(B) any other information that is linked or linkable to an individual, such as medical, educational, financial, and employment information.

(6) RESPONSIBLE AGENCY.—The term “responsible agency” means, with respect to a new Federal PII website, the agency that is responsible for the operation (whether directly or through contracts with other entities) of the website.

(7) SECURE.—The term “secure” means, with respect to a new Federal PII website, that the following requirements are met:

(A) The website is in compliance with subchapter III of chapter 35 of title 44, United States Code.

(B) The website ensures that personally identifiable information elicited, collected, stored, or maintained in connection with the website is captured at the latest possible step in a user input sequence.

(C) The responsible agency for the website has taken reasonable efforts to minimize domain name confusion, including through additional domain registrations.

(D) The responsible agency requires all personnel who have access to personally identifiable information in connection with the website to have completed a Standard Form 85P and signed a non-disclosure agreement with respect to personally identifiable information, and the agency takes proper precautions to ensure only trustworthy persons may access such information.

(E) The responsible agency maintains (either directly or through contract) sufficient personnel to respond in a timely manner to issues relating to the proper functioning and security of the website, and to monitor on an ongoing basis existing and emerging security threats to the website.

(8) STATE.—The term “State” means each State of the United States, the District of Columbia, each territory or possession of the United States, and each federally recognized Indian tribe.

SEC. 3. PRIVACY BREACH REQUIREMENTS.

(a) INFORMATION SECURITY AMENDMENT.—Subchapter III of chapter 35 of title 44, United States Code, is amended by adding at the end the following:

“§3550. Privacy breach requirements

“(a) POLICIES AND PROCEDURES.—The Director of the Office of Management and Budget shall establish and oversee policies and procedures for agencies to follow in the event of a breach of information security involving the disclosure of personally identifiable information, including requirements for—

“(1) not later than 72 hours after the agency discovers such a breach, or discovers evidence that reasonably indicates such a breach has occurred, notice to the individuals whose personally identifiable information could be compromised as a result of such breach;

“(2) timely reporting to a Federal cybersecurity center, as designated by the Director of the Office of Management and Budget; and

“(3) any additional actions that the Director finds necessary and appropriate, including data breach analysis, fraud resolution services, identity theft insurance, and credit protection or monitoring services.

“(b) REQUIRED AGENCY ACTION.—The head of each agency shall ensure that actions taken in response to a breach of information security involving the disclosure of personally identifiable information under the authority or control of the agency comply with policies and procedures established by the Director of the Office of Management and Budget under subsection (a).

“(c) REPORT.—Not later than March 1 of each year, the Director of the Office of Management and Budget shall report to Congress on agency compliance with the policies and procedures established under subsection (a).

“(d) FEDERAL CYBERSECURITY CENTER DEFINED.—The term ‘Federal cybersecurity center’ means any of the following:

“(1) The Department of Defense Cyber Crime Center.

“(2) The Intelligence Community Incident Response Center.

“(3) The United States Cyber Command Joint Operations Center.

“(4) The National Cyber Investigative Joint Task Force.