

via the pain consortium, will go a long way towards increasing research and awareness of chronic pain. I do urge Members to support this legislation.

Mr. Speaker, I reserve the balance of my time.

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

Mrs. CAPPS. Mr. Speaker, I rise in strong support of H.R. 2994, the National Pain Care Policy Act.

I want to thank the chairman of our subcommittee, Mr. PALLONE, for yielding me the time and also for his leadership in making sure this bill has gotten to this point.

I thank the chairman of the full committee, Mr. DINGELL, and our staff who are here and have been working diligently on both sides of the aisle to get this bill to where it is today. I thank our colleague from Michigan, MIKE ROGERS, for his work in paving the way for the passage of this bill today.

The National Pain Care Policy Act would take important steps to improve the coordination of research and treatment of pain. More than 75 million Americans suffer from pain, both chronic and acute, making pain the most common reason Americans access or try to access the health care system.

Yet they often face significant barriers in receiving the proper diagnosis and treatment. Pain is often, too often, only researched and considered as a symptom of another disease, and best practices haven't always been shared across disciplines.

H.R. 2994 would amplify research at the National Institutes of Health and also improve education and outreach efforts for health professionals and the general public alike. I am proud of the significant support we have received in the community from various advocacy groups, health professionals and providers.

I urge all of our colleagues to vote "yes" on H.R. 2994.

AMERICAN ASSOCIATION  
OF NURSE ANESTHETISTS,  
Washington, DC, September 22, 2008.

Hon. LOIS CAPPS,  
House of Representatives,  
Washington, DC.

DEAR CONGRESSWOMAN CAPPS: On behalf of the more than 39,000 members of the American Association of Nurse Anesthetists (AANA), I am pleased to express the Association's support for HR 2994, the National Pain Care Policy Act of 2007.

The AANA is the professional association for Certified Registered Nurse Anesthetists (CRNAs) and student nurse anesthetists, representing over 90 percent of the nurse anesthetists in the United States. CRNAs are advanced practice nurses who administer about 30 million anesthetics to patients each year in the U.S., provide assessment and evaluation for acute and chronic pain and deliver pain management services, and are the sole anesthesia providers in most rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities.

AANA is pleased to support HR 2994, which seeks to eliminate barriers to pain care and improve pain care research, education, and

clinical practice. Recognizing that pain is both a significant public health challenge and a burden to millions of Americans' quality of life, we believe that adoption of the National Pain Care Policy Act would help focus our nation's healthcare research in a new and important way on the cause, prevention, treatment and management of pain. As recognized experts in the field of anesthesia and pain management, America's CRNAs have made substantial contributions to clinical practice in pain care, and help provide millions of patients relief from pain. As HR 2994 would help focus national resources on research and translate research findings into improved clinical practice, we ask that upon the measure's enactment that representatives of the profession of nurse anesthesia be represented on government panels and councils that the legislation authorizes, such as the National Institutes of Health (NIH) National Pain Care Research Advisory Committee, the development of the Institute of Medicine Conference on Pain, the development of the Secretary of Health and Human Services' Public Awareness Campaign on Pain Management, and any others intended to guide and lead this critical healthcare policy agenda. In addition, we ask that grants that the legislation would authorize for expanding education and training to health care professionals in pain care also be made available to accredited nurse anesthesia educational programs.

The AANA applauds the work of the Committee on Energy and Commerce for its bipartisan effort in advancing the National Pain Care Policy Act and will continue working toward its enactment. If we can be of further assistance, please contact Frank Purcell, AANA Senior Director Federal Government Affairs.

Sincerely,

JACKIE S. ROWLES,  
President.

Mr. BURGESS. Mr. Speaker, I would just simply add that many providers, many physicians across the country, will welcome that establishment of parameters and best practices. Oftentimes we feel caught between the situation where do we provide adequate pain relief to our patients and perhaps risk scrutiny from the department of drug enforcement, or do we risk the scrutiny of the patient and their family because of inadequate efforts at pain management.

Oftentimes it can be a fine line and quite a balancing act. I think we will go a long way towards alleviating the suffering of those who are sufferers of chronic and debilitating pain, but also provide additional resources to the caregivers when faced with these difficult situations.

Mr. Speaker, I have no further requests for time on my side, and I will yield back the balance of my time.

Mr. PALLONE. Mr. Speaker, I have no further requests for time. I would urge adoption of this bill dealing with pain care policy and 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. 2994, 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.

Mr. BURGESS. Mr. 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.

#### PAUL D. WELLSTONE MUSCULAR DYSTROPHY COMMUNITY ASSISTANCE, RESEARCH, AND EDUCATION AMENDMENTS OF 2008

Mr. PALLONE. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 5265) to amend the Public Health Service Act to provide for research with respect to various forms of muscular dystrophy, including Becker, congenital, distal, Duchenne, Emery-Dreifuss facioscapulohumeral, limb-girdle, myotonic, and oculopharyngeal, muscular dystrophies, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 5265

*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 2008".

#### SEC. 2. FINDINGS.

The Congress finds as follows:

(1) The muscular dystrophies are devastating diseases that have a significant impact on quality of life—not only for the individual who experiences its painful symptoms and resulting disability, but also for family members and caregivers.

(2) DMD is the most common lethal genetic disorder of childhood worldwide, affecting approximately 1 in every 3,500 boys born each year around the globe. It is characterized by a rapidly progressive muscle weakness that almost always results in death from respiratory or cardiac failure, typically in the late teens or twenties.

(3) Myotonic muscular dystrophy is the second most prominent form of muscular dystrophy and the type most commonly found in adults affecting an estimated 1 in 8,000 people. However, it can affect people of any age—from birth to old age. Described as the most variable disease known in medicine, it is multi-systemic and can cause not only muscle atrophy and myotonia, but also serious cardiac, respiratory, endocrine, gastrointestinal, skeletal and central nervous system complications, as well as problems with the eyes, teeth and hair. As it passes from one generation to the next, it generally worsens with earlier onset. Congenital myotonic muscular dystrophy is the most severe form of myotonic muscular dystrophy affecting infants and causing severe cognitive delays. It often causes sudden death; however, others can live for many years with this slowly degenerative disorder.

(4) Facioscapulohumeral muscular dystrophy (referred to in this section as "FSHD") is the second most prevalent adult muscular dystrophy and the third most prevalent muscular dystrophy of men, women and children. It is inherited genetically and has an estimated incidence of 1 in 20,000 persons. Many leading FSHD scientists note

that the prevalence may be three times higher due to undiagnosed and misdiagnosed cases. FSHD, affecting between 15,000 to 40,000 persons, causes a lifelong progressive and severe loss of all skeletal muscles gradually bringing weakness and reduced mobility. It is genetically transmitted to children, can occur spontaneously, and may affect entire families. Persons with FSHD may also experience hearing loss, vision problems and respiratory insufficiency; some may become severely physically disabled and spend decades in a wheelchair and on a ventilator. FSHD is caused by a novel epigenetic phenomenon not found in other forms of muscular dystrophy and is caused by a contraction of repetitive DNA previously thought to be "junk DNA". The unique epigenetic structure of FSHD is unprecedented in other muscular dystrophies and genetic disorders and demands novel approaches and new research groups. Understanding this mechanism will have great benefit to other areas of biomedical research including cancer and other disease of epigenetic origin.

(5) Congenital muscular dystrophies represent a group of distinct diseases, which begin at birth, with varying severity and involvement of both muscle strength and brain. These diseases often lead to premature infant death, or severely disabled young children who require 24-hour care given their developmental delay compounded by muscle weakness. Other children live to young adulthood and typically require the use of a wheelchair for mobility.

(6) Forms of muscular dystrophy affecting children and adults include Becker, congenital, distal, Duchenne, Emery-Dreifuss, facioscapulohumeral, limb-girdle, myotonic, and oculopharyngeal muscular dystrophies. The limb-girdle muscular dystrophies are of 15 known different types.

(7) Each of the muscular dystrophies, though distinct in progressivity and severity of symptoms, has a devastating impact on hundreds of thousands of children and adults throughout the United States and worldwide, as well as imposes severe physical and economic burdens on those affected. In many of the muscular dystrophies, there are associated medical problems arising from pulmonary issues, respiratory insufficiency, cardiomyopathy, which in many cases is the cause of death for persons with muscular dystrophy.

(8) In the 5 years since enactment of the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (MD-CARE Act) and due directly to the momentum established by the MD-CARE Act, progress has been made in the battle against the Muscular Dystrophies.

(9) Investments made by the Federal Government as a result of the MD-CARE Act include the creation of the MD Coordinating Committee (MDCC), the development of the MDCC Action Plan, establishment of 6 Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers (co-funded, in part, by a national non-profit health organization), development of the Muscular Dystrophy Surveillance, Tracking and Research Network (MD STARnet), and the launch of a comprehensive education and outreach initiative.

(10) In the past few years, the NIH program in translational research in muscular dystrophy has grown significantly and funded a number of large-scale projects to further the development of therapies for muscular dystrophy. As part of this program, the National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) of the National Institutes of Health (NIH) awarded a \$15.4 million, five-year cooperative agreement to develop new

small molecule drugs for the treatment of Duchenne muscular dystrophy (DMD) and potentially other forms of muscular dystrophy as well. The project is a unique research collaboration between private, public, and non-profit partners to build upon previous research and discovery work originally initiated by non-profit partners to identify new treatments for muscular dystrophy. Also through the translational program, three other major cooperative agreements have been awarded for highly targeted therapy development projects in the muscular dystrophies.

(11) Advancements in care have helped prolong life and quality of life for patients with muscular dystrophy.

(12) There remains a shortage of qualified researchers in the field of muscular dystrophy research. Many family physicians and health care professionals still lack the knowledge and resources to detect and properly diagnose muscular dystrophy as early as possible, thus delaying management of symptoms in cases that go undetected or misdiagnosed.

(13) As new understandings of the genetic basis for disease and potential treatment has emerged, the public and health care communities are in urgent need of education and outreach to ensure competent, informed engagement in genetic testing and counseling and appropriate patient characterization so that patients are able to participate in new avenues of research and clinical trials.

(14) As basic research into the muscular dystrophies points the way to new therapeutic targets, there is an urgent need to support the clinical research infrastructure necessary to bring these therapeutic leads to human trials; these infrastructure needs include validated endpoints, current natural history studies, biomarkers, clinical research networks, patient registries and databases.

(15) In order to improve lives and develop effective treatments for individuals with muscular dystrophy, there must be improved communications and partnerships between patients, patient advocacy, researchers, and clinical care providers. To that end, renewed effort to work together by all parties is a critical element for successful outcomes in the years to come.

(16) Continued focus and investment are required to build on the current momentum, respond to public need, and ensure that research and other innovation is translated to therapeutic targets as quickly as possible.

### **SEC. 3. EXPANSION, INTENSIFICATION, AND COORDINATION OF ACTIVITIES OF NIH WITH RESPECT TO RESEARCH ON MUSCULAR DYSTROPHY.**

(a) **TECHNICAL CORRECTION.**—Section 404E of the Public Health Service Act (42 U.S.C. 283g) is amended by striking subsection (f) (relating to reports to Congress) and redesignating subsection (g) as subsection (f).

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

(1) in subsection (a)(1), by inserting "the National Heart, Lung, and Blood Institute," after "the Eunice Kennedy Shriver National Institute of Child Health and Human Development,";

(2) in subsection (b)(1), by adding at the end of the following: "Such centers of excellence shall be known as the 'Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers'"; and

(3) by adding at the end the following:

"(g) **CLINICAL RESEARCH.**—The Coordinating Committee may evaluate the potential need to enhance the clinical research infrastructure required to test emerging therapies for the various forms of muscular dystrophy by prioritizing the achievement of

the goals related to this topic in the plan under subsection (e)(1)."

### **SEC. 4. DEVELOPMENT AND EXPANSION OF ACTIVITIES OF CDC WITH RESPECT TO EPIDEMIOLOGICAL RESEARCH ON MUSCULAR DYSTROPHY.**

Section 317Q of the Public Health Service Act (42 U.S.C. 247b-18) is amended—

(1) by redesignating subsection (d) as subsection (f); and

(2) by inserting after subsection (c) the following:

"(d) **DATA.**—In carrying out this section, the Secretary shall ensure that any data on patients that is collected as part of the Muscular Dystrophy STARnet (under a grant under this section) is regularly updated to reflect changes in patient condition over time.

"(e) **REPORTS AND STUDY.**—

"(1) **ANNUAL REPORT.**—Not later than 18 months after the date of the enactment of the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2008, and annually thereafter, the Director of the Centers for Disease Control and Prevention shall submit to the appropriate committees of the Congress a report—

"(A) concerning the activities carried out by MD STARnet site funded under this section during the year for which the report is prepared;

"(B) containing the data collected and findings derived from the MD STARnet sites each fiscal year (as funded under a grant under this section during fiscal years 2008 through 2012); and

"(C) that every 2 years outlines prospective data collection objectives and strategies.

"(2) **TRACKING HEALTH OUTCOMES.**—The Director of the Centers for Disease Control and Prevention shall provide health outcome data on the health and survival of people with muscular dystrophy."

### **SEC. 5. INFORMATION AND EDUCATION.**

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

(1) by redesignating subsection (c) as subsection (d); and

(2) by inserting after subsection (b) the following:

"(c) **REQUIREMENTS OF CDC.**—In carrying out this section, the Director of the Centers for Disease Control and Prevention shall—

"(1) partner with leaders in the muscular dystrophy patient community; and

"(2) widely disseminate the Duchenne-Becker muscular dystrophy care considerations as broadly as possible, including through partnership opportunities with the muscular dystrophy patient community."

### **SEC. 6. STANDARDS OF CARE.**

Part A of title IX of the Public Health Service Act (42 U.S.C. 299 et seq.) is amended by adding at the end the following:

#### **"SEC. 904. STANDARDS OF CARE RELATING TO MUSCULAR DYSTROPHY.**

"The Director—

"(1) shall evaluate the available scientific evidence for the appropriate medical or patient organizations for purposes of the development and issuance of an initial set of care considerations for Duchenne-Becker muscular dystrophy and provide periodic review and updates where appropriate; and

"(2) may replicate the same methodology used to develop the Duchenne-Becker muscular dystrophy care considerations developed under paragraph (1) as a model for other muscular dystrophies."

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

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

The Chair recognizes the gentleman from New Jersey.

#### GENERAL LEAVE

Mr. PALLONE. Mr. Speaker, I ask unanimous consent that all Members may 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 gentleman from New Jersey?

There was no objection.

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

Mr. Speaker, I rise in support of H.R. 5265, the Paul Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2008, a bill to reauthorize programs at the National Institutes of Health and the Centers for Disease Control and Prevention for research on various forms of muscular dystrophy.

Duchenne-Becker muscular dystrophy, DBMD, is a combined spectrum of a genetic disorder. DBMD is usually diagnosed when the child is 3 to 6 years of age. Early signs include delays in walking and frequent falling. As the child grows older, muscle deterioration continues to progress until, finally, the disease reaches a fatal conclusion in the teen years.

Enacting H.R. 5265 would make a number of improvements to current programs at the NIH and CDC. It would allow the interagency coordinating committee for muscular dystrophy to give special consideration to enhancing the clinical research infrastructure required to test emerging therapies for the various forms of muscular dystrophy, require the director of the CDC to report on muscular dystrophy surveillance, tracking, and research network data collection and provide for respective health outcome data on the health and survival of people with muscular dystrophy and require the director of the Agency for Health Care Research and Quality to evaluate the available scientific evidence to develop and issue an initial set of care considerations for DBMD and provide ongoing review and updates. All of the above coordinated research and tracking efforts will continue to lead us down a path towards one day finding a cure for this tragic condition.

I want to thank my colleague on the Commerce Committee, Congressman ENGEL of New York, for his leadership on this legislation. He has been working on this bill for a long time, and I appreciate his efforts to craft a strong bipartisan product.

I fully support H.R. 5265 and urge my colleagues to join me in its adoption.

Mr. Speaker, I reserve the balance of my time.

Mr. BURGESS. Mr. Speaker, I yield myself such time as I may consume, and I rise in support of H.R. 5265, the Paul D. Wellstone Muscular Dystrophy

Community Assistance, Research, and Education Amendments of 2008. I want to commend Congressman ENGEL for bringing this bill, and I was also proud to be the lead minority cosponsor on this bill.

H.R. 5265 reauthorizes the existing Centers for Disease Control efforts towards muscular dystrophy. The muscular dystrophies are a group of more than 30 genetic diseases characterized by progressive weakness and degeneration of the skeletal muscles that control voluntary movement. Muscular dystrophy funding is used for surveillance and family needs and assessment activities.

I am supportive of the bill's efforts to reauthorize and improve the existing muscular dystrophy registry at the Centers for Disease Control, and I urge Members to support the legislation.

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

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Mr. PALLONE. Mr. Speaker, I have no further requests for time, and I urge adoption of this bill, the Paul Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2008.

Mr. ENGEL. Mr. Speaker, I am so proud that today we will move to pass H.R. 5265, the Paul D. Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2008. Today we have over 120 bipartisan cosponsors, as well as the support of the medical community.

Muscular dystrophy is a genetic disease which results in progressive degeneration of skeletal muscles and other organs, notably the heart. There are nine muscular dystrophies affecting over 300,000 individuals in the United States. The most lethal is Duchenne muscular dystrophy, which affects 1 in every 3,500 boys. There is no cure.

Prior to 2001, there were few resources directed toward research and development of therapies and care models for those afflicted with muscular dystrophy. To address this issue, the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 was introduced. Congress overwhelmingly supported the legislation. Unfortunately, the authorization for this work expired in 2006.

The 2001 law specified a number of provisions for expanding and intensifying research on muscular dystrophy. These efforts included the establishment of six scientific centers of excellence, the creation of a Muscular Dystrophy Coordinating Committee (MDCC) to develop plans for supporting research and education on muscular dystrophy, and an expansion by the Centers for Disease Control and Prevention (CDC) into epidemiological activities regarding muscular dystrophy.

The reauthorization of the Paul D. Wellstone MD-CARE Amendments officially names the Centers of Excellence the Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers. In addition, it ensures that data collection at CDC is updated regularly with a requirement for regular reports to Congress. The bill also requires the Agency for Healthcare Research and Quality to work with appropriate medical or patient organizations to finalize an

initial set of care considerations and for CDC to disseminate that information to targeted audiences.

Once again, thank you Mr. Speaker for your commitment to muscular dystrophy.

I know this bill will have a profound effect on so many families in America upon enactment.

Mr. PALLONE. 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. 5265, 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.

Mr. BURGESS. Mr. 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.

#### METH FREE FAMILIES AND COMMUNITIES ACT

Mr. PALLONE. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 6901) to amend the Public Health Service Act to provide for the establishment of a drug-free workplace information clearinghouse, to support residential methamphetamine treatment programs for pregnant and parenting women, to improve the prevention and treatment of methamphetamine addiction, and for other purposes.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 6901

*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 "Meth Free Families and Communities Act".

#### SEC. 2. ENHANCING HEALTH CARE PROVIDER AWARENESS OF METHAMPHETAMINE ADDICTION.

Section 507(b) of the Public Health Service Act (42 U.S.C. 290bb(b)) is amended—

(1) by redesignating paragraphs (13) and (14) as paragraphs (14) and (15), respectively; and

(2) by inserting after paragraph (12) the following:

“(13) collaborate with professionals in the addiction field and primary health care providers to raise awareness about how to—

“(A) recognize the signs of a substance abuse disorder; and

“(B) apply evidence-based practices for screening and treating individuals with or at-risk for developing an addiction, including addiction to methamphetamine or other drugs.”.

#### SEC. 3. RESIDENTIAL TREATMENT PROGRAMS FOR PREGNANT AND PARENTING WOMEN.

Section 508 of the Public Health Service Act (42 U.S.C. 290bb-1) is amended—