PRENATALLY AND POSTNATALLY DIAGNOSED CONDITIONS AWARENESS ACT

Mr. PALLONE. Madam Speaker, I move to suspend the rules and pass the Senate bill (S. 1810) to amend the Public Health Service Act to increase the provision of scientifically sound information and support services to patients receiving a positive test diagnosis for Down's syndrome or other prenatally and postnatally diagnosed conditions.

The Clerk read the title of the Senate bill.

The text of the Senate bill is as follows:

S. 1810

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 ''Prenatally and Postnatally Diagnosed Conditions Awareness Act''.

SEC. 2. PURPOSES.

It is the purpose of this Act to—

(1) increase patient referrals to providers of key support services for women who have received a positive diagnosis for Down syndrome, or other prenatally or postnatally diagnosed conditions, as well as to provide up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes;

(2) strengthen existing networks of support through the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and other patient and provider outreach programs; and

(3) ensure that patients receive up-to-date, evidence-based information about the accuracy of the test.

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. SUPPORT FOR PATIENTS RECEIVING A POSITIVE DIAGNOSIS OF DOWN SYNDROME OR OTHER PRENATALLY OR POSTNATALLY DIAGNOSED CONDITIONS.

''(a) DEFINITIONS.—In this section:

''(1) DOWN SYNDROME.—The term 'Down syndrome' refers to a chromosomal disorder caused by an error in cell division that results in the presence of an extra whole or partial copy of chromosome 21.

''(2) HEALTH CARE PROVIDER.—The term 'health care provider' means any person or entity required by State or Federal law or regulation to be licensed, registered, or certified to provide health care services, and who is so licensed, registered, or certified.

''(3) POSTNATALLY DIAGNOSED CONDITION.—The term 'postnatally diagnosed condition' means any health condition identified during the 12-month period beginning at birth.

''(4) PRENATALLY DIAGNOSED CONDITION.—The term 'prenatally diagnosed condition' means any fetal health condition identified by prenatal genetic testing or prenatal screening procedures.

''(5) PRENATAL TEST.—The term 'prenatal test' means diagnostic or screening tests offered to pregnant women seeking routine prenatal care that are administered on a required or recommended basis by a health care provider based on medical history, family background, ethnic background, previous test results, or other risk factors.

''(b) INFORMATION AND SUPPORT SERVICES.—

''(1) IN GENERAL.—The Secretary, acting through the Director of the National Institutes of Health, the Director of the Centers for Disease Control and Prevention, or the Administrator of the Health Resources and Services Administration, may authorize and oversee certain activities, including the awarding of grants, contracts or cooperative agreements to eligible entities, to—

''(A) collect, synthesize, and disseminate current evidence-based information relating to Down syndrome or other prenatally or postnatally diagnosed conditions; and

''(B) coordinate the provision of, and access to, new or existing supportive services for patients receiving a positive diagnosis for Down syndrome or other prenatally or postnatally diagnosed conditions, including—

''(i) the establishment of a resource telephone hotline accessible to patients receiving a positive test result or to the parents of newly diagnosed infants with Down syndrome and other diagnosed conditions;

''(ii) the expansion and further development of the National Dissemination Center for Children with Disabilities, so that such Center can more effectively conduct outreach to new and expecting parents and provide them with up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes;

''(iii) the expansion and further development of national and local peer-support programs, so that such programs can more effectively serve women who receive a positive diagnosis for Down syndrome or other prenatal conditions or parents of infants with a postnatally diagnosed condition;

''(iv) the establishment of a national registry, or network of local registries, of families willing to adopt newborns with Down syndrome or other prenatally or postnatally diagnosed conditions, and links to adoption agencies willing to place babies with Down syndrome or other prenatally or postnatally diagnosed conditions, with families willing to adopt; and

''(v) the establishment of awareness and education programs for health care providers who provide, interpret, or inform parents of the results of prenatal tests for Down syndrome or other prenatally or postnatally diagnosed conditions, to patients, consistent with the purpose described in section 2(b)(1) of the Prenatally and Postnatally Diagnosed Conditions Awareness Act.

''(2) ELIGIBLE ENTITY.—In this subsection, the term 'eligible entity' means—

''(A) a State or a political subdivision of a State;

''(B) a consortium of 2 or more States or political subdivisions of States;

''(C) a territory;

''(D) a health facility or program operated by or pursuant to a contract with or grant from the Indian Health Service; or

''(E) any other entity with appropriate expertise in prenatally and postnatally diagnosed conditions (including nationally recognized disability groups), as determined by the Secretary.

''(3) DISTRIBUTION.—In distributing funds under this subsection, the Secretary shall place an emphasis on funding partnerships between health care professional groups and disability advocacy organizations.

''(c) PROVISION OF INFORMATION TO PROVIDERS.—

''(1) IN GENERAL.—A grantee under this section shall make available to health care providers of parents who receive a prenatal or postnatal diagnosis the following:

''(A) Up-to-date, evidence-based, written information concerning the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes.

''(B) Contact information regarding support services, including information hotlines specific to Down syndrome or other prenatally or postnatally diagnosed conditions, resource centers or clearinghouses, national and local peer support groups, and other education and support programs as described in subsection (b)(2).

''(2) INFORMATIONAL REQUIREMENTS.—Information provided under this subsection shall be—

''(A) culturally and linguistically appropriate as needed by women receiving a positive prenatal diagnosis or the family of infants receiving a postnatal diagnosis; and

''(B) approved by the Secretary.

''(d) REPORT.—Not later than 2 years after the date of enactment of this section, the Government Accountability Office shall submit a report to Congress concerning the effectiveness of current healthcare and family support programs serving as resources for the families of children with disabilities.''.

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 may have 5 legislative days in which to revise and extend their remarks and include extraneous material on the bill under consideration.

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

There was no objection.

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

Madam Speaker, I rise in support of S. 1810, the Prenatally and Postnatally Diagnosed Condition Awareness Act, legislation introduced by Senator BROWNBACK.

Madam Speaker, this legislation would ensure that pregnant women or mothers of newborns with a prenatally or postnatally diagnosed condition have timely access to updated, scientific information about the life expectancy, intellectual and functional development and treatment options for their child.

In addition, this legislation would provide families with referrals to support services; improve our Nation's epidemiological understanding of prenatally and postnatally diagnosed conditions; and support health care providers to provide the results of prenatal or postnatal tests to patients.

I would like to once again thank all of my colleagues, especially Mr. SENSENBRENNER, the sponsor of the House companion legislation, for all of their hard work. I urge my colleagues on both sides of the aisle to support its passage.

I reserve the balance of my time.

Mr. DEAL of Georgia. Madam Speaker, at this time I would like to yield such time she may consume to Representative MCMORRIS Rodgers.

Mrs. McMORRIS RODGERS. Madam Speaker, I rise in strong support of Senate bill 1810, the Prenatally and Postnatally Diagnosed Conditions Awareness Act. I believe that this bill is a positive step forward in helping new and expecting parents of children with special needs get accurate information on the real potential of their children. This sort of information is critical at the time of diagnosis.

This legislation is very important to me because I am the proud mother of an amazing baby boy, Cole McMorris Rodgers. Two years ago my life changed when I found out I was expecting my first child, and it changed even more dramatically when Cole was born a month early and he was diagnosed with Down syndrome. Cole turned a year old in April; and looking back on the last year, I can't imagine life without him.

Everywhere I go, I have met people who share their stories of being touched by a loved one with special needs. They always share with me the positive impacts that this person has had in their life. It has helped me see just a glimpse of the amazing impact that my son is going to have on our lives as well as this world.

The bill we are considering today will help parents who either receive news that their child may be born with a genetic disorder or some other abnormality, or a child that has been diagnosed from birth up until 12 months of age, with current and reliable information about the many services and support networks available.

When new and expecting parents are told that their child will have some kind of genetic disorder, it is a very difficult and sometimes an overwhelming experience. And yet a study by Louis Harris and Associates found that medical professionals are more likely than any other group to underestimate the quality of life experienced by people with disabilities.

This situation is not due to a lack of will by parent support groups or disability advocacy groups. These organizations have tried countless ways to reach out to parents who have received a prenatal diagnosis. Unfortunately, many geneticists and OB–GYNs believe that parents of children with these conditions and adults living with these conditions are biased.

Specifically, this bill provides for the establishment of a resource telephone hotline, a Web site, and the expansion of the leading information clearinghouse on disabilities so that it can more effectively provide parents with accurate and up-to-date information on their child's condition, along with the available resources and services.

I applaud the work of Senators BROWNBACK and KENNEDY for their great work on this important bill. Their commitment to the disability community is commendable, and I urge colleagues on both sides of the aisle to join me in support of S. 1810.

Madam Speaker, I rise today in strong support for S. 1810, the Prenatally and Postnatally Diagnosed Conditions Awareness Act. I believe this bill is a positive step forward in helping new and expecting parents of children with special needs get accurate information on the real potential of their children. This sort of information is critical at the time of diagnosis.

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Everywhere I go, I've met people who share their stories about a loved one who has special needs and they always share with me the positive impact that this person had in their life. It has helped me see a glimpse of the amazing impact my son is going to have on our lives and in this world.

Because of my personal experiences with my son Cole, I have made it my personal goal to increase awareness of the capabilities, value, and worth of people with disabilities. I am committed to helping families and individuals with disabilities have an opportunity to lead full, happy and productive lives.

Today, because of the advances in technology, we offer diagnosis for Down syndrome prenatally and soon we will be able to diagnose other genetic disorders and diseases prenatally. The question is every person in America is, "what are we going to do with this information and help parents when they receive the news of a diagnosis?"

The bill we are considering today will help parents who either receive the news that their child may be born with a disability, or their child has been diagnosed from birth up until 12 months of age, with current and reliable information about the many services and support networks available. This is a distressing and confusing time for parents of special children and it is so important for them to know that they are not alone, others have struggled with the same questions, and answers are available.

When new or expecting parents are told that their child will have a disability it is a very difficult and sometimes overwhelming experience. And yet, a study by Louis Harris and Associates found that medical professionals are more likely than any other group to underestimate the quality of life experienced by people with disabilities.

This situation is not due to a lack of will by the parent support groups and disability advocacy groups. These organizations have tried countless ways to reach out to parents who have received prenatal diagnoses of various conditions. Unfortunately, many geneticists and OB–GYNs believe that the parents of children with these conditions and the adults living with these conditions are biased.

Specifically, this bill provides for the establishment of a resource telephone hotline, a Web site, and the expansion of the leading information clearinghouse on disability, so that it can more effectively provide parents with accurate, up-to-date information on their child's condition along with available resources and services. S. 1810 also provides for the expansion and development of national and local parent support programs, so that they can more effectively reach out to new parents. In addition, this bill establishes a national registry of parents willing to adopt children with these disabilities. Finally, it establishes awareness and education programs for health care providers who give parents the results of these tests.

I applaud the work of Senators BROWNBACK and KENNEDY for their great work on this important bill. Their commitment to the disability community is commendable. I urge my colleagues on both sides of the aisle to join me in support of passage of S. 1810, the Prenatally and Postnatally Diagnosed Conditions Awareness Act. I hope that this bill will provide these parents with the information and support they so desperately need during a critical time.

Mr. PALLONE. Madam Speaker, I yield 2 minutes to the gentleman from Ohio (Mr. RYAN).

Mr. RYAN of Ohio. I thank the gentleman for the opportunity.

I am proud to have joined as the lead Democratic cosponsor with the gentleman from Wisconsin (Mr. SENSENBRENNER) on the House version of this legislation. I would like to thank Mr. SENSENBRENNER, Senator BROWNBACK, and Senator KENNEDY for their leadership in moving this bill.

Last year, Congresswoman DELAURO and I introduced legislation called Reducing the Need for Abortions and Supporting Parents Act which contains a provision similar to what is in this bill before us now.

What this bill does is make a commitment to new and expectant mothers whose child receives a diagnosis for Down syndrome or other prenatally or postnatally diagnosed conditions. Society will be there, and it tells them that society will be there to support you. We will bring every resource to bear to ensure that you are able to raise a beautiful baby.

Never should a pregnant woman feel that her options are limited by a lack of public support for the types of social services that could help her, her family, and her baby.

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The sad reality, Madam Speaker, is that over 90 percent of pregnancies with a diagnosis of Down Syndrome are aborted. This should not and need not be the case. We have not done enough to help these women and their families. We must do more to get them the support they need, the support they deserve, and this bill is a crucial step in that direction.

Lastly, I would like to thank Speaker PELOSI, Minority Leader BOEHNER and my friends on the other side of the aisle for working together to get this common ground legislation passed.

Mr. DEAL of Georgia. Madam Speaker, I am pleased to yield to one of the leaders on this subject matter here in the House, the gentleman from Wisconsin (Mr. SENSENBRENNER).

Mr. SENSENBRENNER. Madam Speaker, I'm pleased that the House is considering Senate 1810, the Prenatally and Postnatally Diagnosed Conditions Awareness Act. This bill would ensure that families who receive a diagnosis of Down Syndrome or any other condition, prenatally or up to a year after birth, receive information, referrals and support in a number of ways.

I first introduced the House companion bill in 2005. Research has indicated that when parents are confronted with a complex prenatal test result indicating their child may be born with a level of disability, they're not receiving comprehensive information regarding the accuracy of the test, nor are they receiving up-to-date information regarding life expectancy, developmental potential or quality of life of individuals with these disabilities.

Mothers of children born with Down Syndrome have reported that doctors did not tell them about the potential of people with Down Syndrome, nor did they feel like they received contact information for parent support groups. This is unfortunate, particularly in light of mothers reporting that the shortcomings were happening at an emotional time.

This Act will require health care providers who deliver a positive test diagnosis to also deliver referrals to key support services in the community, as well as up-to-date science-based information about the life expectancy, developmental potential and treatment options for individuals with prenatally diagnosable conditions. The accuracy and integrity of this information is of the utmost importance.

Patients would be provided with support through the Centers for Disease Control patient and provider outreach programs. A hot line and Web site for newly diagnosed patients would be established, and peer support groups and network would be formed to provide personal support.

My wife, Cheryl, has a sister living with Down Syndrome. I have witnessed firsthand what a wonderful and capable woman my sister-in-law has become. Tara Rae Warren completed her high school education, is financially independent, and lectures to students of special education on the challenges of the disability. Cheryl's family has always been there for her, and we have worked through the challenges by having a positive support structure.

My hope is that all families with diagnosed children can gain access to positive current information and the network of supportive families. Informed decision-making is better for everyone involved.

I urge my colleagues to join me in support of this important bill.

Mr. PALLONE. Madam Speaker, I have no further speakers, and I yield back the balance of my time and ask that everyone support this legislation.

Mr. DEAL of Georgia. Madam Speaker, I urge my colleagues to join us in taking this very first important step of dealing with the care and the quality of care for individuals who suffer from Down Syndrome and for their families. I urge the adoption of this legislation.

I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from New Jersey (Mr. PALLONE) that the House suspend the rules and pass the Senate bill, S. 1810.

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

A motion to reconsider was laid on the table.

POISON CENTER SUPPORT, ENHANCEMENT, AND AWARENESS ACT OF 2008

Mr. PALLONE. Madam Speaker, I move to suspend the rules and pass the Senate bill (S. 2932) to amend the Public Health Service Act to reauthorize the poison center national toll-free number, national media campaign, and grant program to provide assistance for poison prevention, sustain the funding of poison centers, and enhance the public health of people of the United States.

The Clerk read the title of the Senate bill.

The text of the Senate bill is as follows:

S. 2932

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 ''Poison Center Support, Enhancement, and Awareness Act of 2008''.

SEC. 2. FINDINGS.

Congress makes the following findings:

(1) Poison control centers are the primary defense of the United States against injury and deaths from poisoning. Twenty-four hours a day, the general public as well as health care practitioners contact their local poison control centers for help in diagnosing and treating victims of poisoning. In 2007, more than 4,000,000 calls were managed by poison control centers providing ready and direct access for all people of the United States, including many underserved populations in the United States, with vital emergency public health information and response.

(2) Poisoning is the second most common form of unintentional death in the United States. In any given year, there will be between 3,000,000 and 5,000,000 poison exposures. Sixty percent of these exposures will involve children under the age of 6 who are exposed to toxins in their home. Poisoning accounts for 285,000 hospitalizations, 1,200,000 days of acute hospital care, and more than 26,000 fatalities in 2005.

(3) In 2008, the Harvard Injury Control Research Center reported that poisonings from accidents and unknown circumstances more than tripled in rate since 1990. In 2005, the last year for which data are available, 26,858 people died from accidental or unknown poisonings. This represents an increase of 20,000 since 1990 and an increase of 2,400 between 2004 and 2005. Fatalities from poisoning are increasing in the United States in near epidemic proportions. The funding of programs to reverse this trend is needed now more than ever.

(4) In 2004, The Institute of Medicine of the National Academy of Sciences recommended that ''Congress should amend the current Poison Control Center Enhancement and Awareness Act Amendments of 2003 to provide sufficient funding to support the proposed Poison Prevention and Control System with its national network of poison centers. Support for the core activities at the current level of service is estimated to require more than $100 million annually.''.

(5) Sustaining the funding structure and increasing accessibility to poison control centers will promote the utilization of poison control centers and reduce the inappropriate use of emergency medical services and other more costly health care services. The 2004 Institute of Medicine Report to Congress determined that for every $1 invested in the Nation's poison control centers $7 of health care costs are saved. In 2005, direct Federal health care program savings totaled in excess of $525,000,000 as the result of poison control center public health services.

(6) More than 30 percent of the cost savings and financial benefits of the Nation's network of poison control centers are realized annually by Federal health care programs (estimated to be more than $1,000,000,000), yet Federal funding support (as demonstrated by the annual authorization of $30,100,000 in Public Law 108–194) comprises less than 11 percent of the annual network expenditures of poison centers.

(7) Real-time data collected from the Nation's certified poison control centers can be an important source of information for the detection, monitoring, and response for contamination of the air, water, pharmaceutical, or food supply.

(8) In the event of a terrorist event, poison control centers will be relied upon as a critical source for accurate medical information and public health emergency response concerning the treatment of patients who have had an exposure to a chemical, radiological, or biological agent.

SEC. 3. REAUTHORIZATION OF POISON CONTROL CENTERS NATIONAL TOLL-FREE NUMBER.

Section 1271 of the Public Health Service Act (42 U.S.C. 300d–71) is amended to read as follows:

''SEC. 1271. MAINTENANCE OF THE NATIONAL TOLL-FREE NUMBER.

''(a) In General.—The Secretary shall provide coordination and assistance to poison control centers for the establishment of a nationwide toll-free phone number, and the maintenance of such number, to be used to access such centers.

''(b) Authorization of Appropriations.—There is authorized to be appropriated $2,000,000 for fiscal year 2009 to carry out this section, and $700,000 for each of fiscal years 2010 through 2014 for the maintenance of the nationwide toll free phone number under subsection (a).''.

SEC. 4. REAUTHORIZATION OF NATIONWIDE MEDIA CAMPAIGN TO PROMOTE POISON CONTROL CENTER UTILIZATION.

(a) In General.—Section 1272 of the Public Health Service Act (42 U.S.C. 300d–72) is amended to read as follows:

''SEC. 1272. NATIONWIDE MEDIA CAMPAIGN TO PROMOTE POISON CONTROL CENTER UTILIZATION.

''(a) In General.—The Secretary shall carry out, and expand upon, a national media campaign to educate the public and health care providers about poison prevention and the availability of poison control center resources in local communities and to conduct advertising campaigns concerning the nationwide toll-free number established under section 1271(a).

''(b) Contract With Entity.—The Secretary may carry out subsection (a) by entering into contracts with one or more public or private entities, including nationally recognized organizations in the field of poison control and national media firms, for the