

to the floor. Along with my fellow Texan, Mr. GENE GREEN, I introduced this bill in 2016 following that particularly traumatic incident that struck so close to home.

Texas is not unique in its need for this expertise. Over the last few months alone, our Nation has witnessed a need for trauma care hospitals across the country. One such incident was the Amtrak derailment near Dupont, Washington, on December 18, 2017. That incident resulted in 3 passenger fatalities and 70 injuries over a busy freeway.

As we have seen, having access to experienced trauma care can become the difference between life and death for a critically injured patient. There is no doubt that integrating military physicians into the trauma and disaster system is beneficial not only for American patients, but also for American soldiers.

I am encouraged by the bipartisan effort to support both our servicemen and our Nation's trauma system, and I thank the cosponsors from both sides of the aisle for their support of this important legislation.

Quite simply, the MISSION ZERO Act is common sense, and I urge Members to join me in supporting this life-saving legislation.

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

□ 1715

Mr. GENE GREEN of Texas. Mr. Speaker, I yield myself such time as I may consume.

Mr. Speaker, I rise in strong support of H.R. 880, the Military Injury Surgical Systems Integrated Operationally Nationwide to Achieve ZERO Preventable Deaths Act, or MISSION ZERO Act.

I am proud to have worked closely with Energy and Commerce Subcommittee on Health Chairman BURGESS and my colleagues from Florida and North Carolina, Representative CASTOR and Representative HUDSON, on this legislation.

The MISSION ZERO Act will help us move towards a trauma system that achieves the goal of zero preventable traumatic deaths.

Whether in response to a gruesome sports injury, a car accident on the highway, or, unfortunately, a tragic event like the recent school shooting in Parkland, Florida, Americans of all ages and backgrounds depend on our trauma care system to respond with skilled experts to provide the services necessary to save lives and prevent disability.

The MISSION ZERO Act will help us ensure access to quality trauma care based on the best available evidence by establishing a grant program to assist civilian trauma centers to partner with military trauma professionals. This partnership will benefit our civilian trauma centers by increasing the availability of trauma professionals to serve in trauma centers across the United States.

This partnership will benefit our military trauma system by allowing trauma professionals to maintain their trauma care capabilities during times of peace and help ensure they are prepared to meet the needs of our heroes on the battlefield.

I urge my colleagues to support this legislation and help ensure that Americans in need of trauma services, whether civilian or in the Armed Forces, receive the highest quality of care possible.

Mr. Speaker, I yield such time as she may consume to the gentlewoman from Florida (Ms. CASTOR), the cosponsor of the bill, and I thank the cosponsors of this bill for serving on the Energy and Commerce Committee.

Ms. CASTOR of Florida. Mr. Speaker, I rise in strong support of the MISSION ZERO Act, H.R. 880, and I would like to thank Chairman BURGESS, Ranking Member GENE GREEN from Texas, and Mr. HUDSON from North Carolina for sponsoring this legislation with me.

The MISSION ZERO Act will assist the Department of Defense in assigning trauma surgeons to our civilian trauma centers. It will help fill the gap that we currently have in care recently examined by the National Academies of Sciences, Engineering, and Medicine.

The MISSION ZERO Act will establish grant initiatives for eligible trauma systems to incorporate full military trauma teams or individual military trauma providers into our hospitals—the ones that have busy emergency rooms.

This mutually beneficial partnership will allow civilian doctors and nurses and care providers the chance to learn more about military best practices and will give our military trauma care providers the opportunity to utilize their cutting-edge expertise without leaving the military.

I have seen this initiative in action already back home in Tampa at Tampa General Hospital, located just a few miles down the road from MacDill Air Force Base, which is home to U.S. Central Command, U.S. Special Operations Command, and the 6th Air Mobility Wing, which is also home to the 6th Air Medical Group.

Since about 2011, they have had an ongoing partnership to do just what this bill provides: create a lot of energy and shared expertise in the civilian trauma center at Tampa General Hospital and bring in the military specialists so they can continue to hone their caregiving and craft. They use nurses, surgeons, and all sorts of specialists.

The initiative allows military and civilian medical teams to work in the most intense trauma environments—that is, our level one trauma center—and take very good care of folks all across central Florida. These partnerships are vital for continued training for our community and our military.

I think Dr. BURGESS and Mr. GENE GREEN from Texas are doing a great service by replicating this in other trauma centers across the United States.

The MISSION ZERO Act is endorsed by the American Congress of Neurological Surgeons, American College of Emergency Physicians, American College of Surgeons, and the Trauma Care Association of America.

Again, I thank Dr. BURGESS, Ranking Member GENE GREEN from Texas, Mr. HUDSON, and all my Energy and Commerce colleagues, and I urge everyone here in the House to support this important bill.

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

Mr. BURGESS. Mr. Speaker, this is an important bill. I urge my colleagues to support it, and I yield back the balance of my time.

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. 880, 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.

#### CONGENITAL HEART FUTURES REAUTHORIZATION ACT OF 2017

Mr. BURGESS. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 1222) to amend the Public Health Service Act to coordinate Federal congenital heart disease research efforts and to improve public education and awareness of congenital heart disease, and for other purposes, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 1222

*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 "Congenital Heart Futures Reauthorization Act of 2017".*

##### SEC. 2. NATIONAL CONGENITAL HEART DISEASE SURVEILLANCE SYSTEM.

*Section 399V-2 of the Public Health Service Act (42 U.S.C. 280g-13) is amended to read as follows:*

##### "SEC. 399V-2. NATIONAL CONGENITAL HEART DISEASE RESEARCH, SURVEILLANCE, AND AWARENESS.

*"(a) IN GENERAL.—The Secretary shall—*

*"(1) enhance and expand research and surveillance infrastructure to study and track the epidemiology of congenital heart disease (in this section referred to as 'CHD'); and*

*"(2) award grants to eligible entities to undertake the activities described in this section.*

*"(b) NATIONAL CONGENITAL HEART DISEASE STUDY.—*

*"(1) IN GENERAL.—The Secretary shall plan, develop, implement, and submit one or more reports to the Congress on a study to improve understanding of the epidemiology of CHD across the lifespan, from birth to adulthood, with particular interest in the following:*

*"(A) Health care utilization of those affected by CHD.*

*"(B) Demographic factors associated with CHD, such as age, race, ethnicity, gender, and family history of individuals who are diagnosed with the disease.*

*"(C) Outcome measures, such that analysis of the outcome measures will allow derivation of*

evidence-based best practices and guidelines for CHD patients.

“(2) PERMISSIBLE CONSIDERATIONS.—The study under this subsection may—

“(A) gather data on the health outcomes of a diverse population of those affected by CHD;

“(B) consider health disparities among those affected by CHD, which may include the consideration of prenatal exposures; and

“(C) incorporate behavioral, emotional, and educational outcomes of those affected by CHD.

“(3) PUBLIC ACCESS.—Data generated from the study under this subsection shall be made available—

“(A) for purposes of CHD research, subject to appropriate protections of personal privacy, including protections required by paragraph (4); and

“(B) to the public, subject to paragraph (4) and with appropriate exceptions for protection of personal privacy.

“(4) PATIENT PRIVACY.—The Secretary shall ensure that the study under this subsection is carried out in a manner that complies with the requirements applicable to a covered entity under the regulations promulgated pursuant to section 264(c) of the Health Insurance Portability and Accountability Act of 1996.

“(c) ELIGIBILITY FOR GRANTS.—To be eligible to receive a grant under subsection (a)(2), an entity shall—

“(1) be a public or private nonprofit entity with specialized experience in CHD; and

“(2) submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

“(d) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there is authorized to be appropriated \$4,000,000 for each of fiscal years 2018 through 2022.”

### SEC. 3. CONGENITAL HEART DISEASE RESEARCH.

Section 425 of the Public Health Service Act (42 U.S.C. 285b–8) is amended to read as follows:

#### “SEC. 425. CONGENITAL HEART DISEASE.

“(a) IN GENERAL.—The Director of the Institute may expand, intensify, and coordinate research and related activities of the Institute with respect to congenital heart disease, which may include congenital heart disease research with respect to—

“(1) causation of congenital heart disease, including genetic causes;

“(2) long-term outcomes in individuals with congenital heart disease, including infants, children, teenagers, adults, and elderly individuals;

“(3) diagnosis, treatment, and prevention;

“(4) studies using longitudinal data and retrospective analysis to identify effective treatments and outcomes for individuals with congenital heart disease; and

“(5) identifying barriers to lifelong care for individuals with congenital heart disease.

“(b) COORDINATION OF RESEARCH ACTIVITIES.—The Director of the Institute may coordinate research efforts related to congenital heart disease among multiple research institutions and may develop research networks.

“(c) MINORITY AND MEDICALLY UNDERSERVED COMMUNITIES.—In carrying out the activities described in this section, the Director of the Institute shall consider the application of such research and other activities to minority and medically underserved communities.

“(d) REPORT FROM NIH.—Not later than one year after the date of the enactment of the Congenital Heart Futures Reauthorization Act of 2017, the Director of NIH, acting through the Director of the Institute, shall provide a report to Congress—

“(1) outlining the ongoing research efforts of the National Institutes of Health regarding congenital heart disease; and

“(2) identifying—

“(A) future plans for research regarding congenital heart disease; and

“(B) the areas of greatest need for such research.”

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

The Chair recognizes the gentleman from Texas (Mr. BURGESS).

#### 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 material 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, I rise today in support of H.R. 1222, the Congenital Heart Futures Reauthorization Act, introduced by my Energy and Commerce colleague, Representative GUS BILIRAKIS from Florida.

This important initiative will enhance current Federal efforts addressing congenital heart disease, which is the most common birth defect and leading cause of mortality in infants. This bipartisan legislation enhances research and surveillance at the Centers for Disease Control and Prevention, awards grants to further study congenital heart disease, and directs the National Institutes of Health to report on their current research efforts in this space.

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

Mr. GENE GREEN of Texas. Mr. Speaker, I yield myself such time as I may consume.

Mr. Speaker, I rise in support of H.R. 1222, the Congenital Heart Futures Reauthorization Act, led by Congressman BILIRAKIS and Congressman SCHIFF from California.

This legislation reauthorizes the Congenital Heart Futures Act, which was enacted in 2010, as part of the Affordable Care Act.

The Congenital Heart Futures Reauthorization Act builds on the success of current efforts by the Centers for Disease Control and Prevention to improve and expand research, monitoring, and public outreach and educational programs relating to congenital heart disease.

This bill requires the National Institutes of Health to issue a report outlining current and future research plans with respect to congenital heart disease.

Each year, more than 40,000 babies are born in the United States with a congenital heart defect. One million children and 1.4 million adults are currently living with congenital heart disorders. Individuals living with a congenital heart disease often require specialized care and remain at risk of disability or premature death throughout their life.

More research and surveillance is needed to improve our knowledge of

why congenital heart defects develop and how they can be effectively treated. This legislation will help expand our understanding of congenital heart disease across the lifespan and has the potential to improve the lives of the millions of children and adults living with congenital heart disease in America.

Mr. Speaker, I urge my colleagues to support this measure, and I reserve the balance of my time.

Mr. BURGESS. Mr. Speaker, I yield 5 minutes to the gentleman from Florida (Mr. BILIRAKIS), the principal author of this bill.

Mr. BILIRAKIS. Mr. Speaker, I rise today in support of H.R. 1222, the Congenital Heart Futures Reauthorization Act, which will reauthorize and ensure continued investment in surveillance research to assess the lifelong needs of individuals with congenital heart defects, or CHDs.

These surveillance efforts will help improve our understanding of CHD across the lifespan, from birth to adulthood. This research will help us learn more about demographic factors such as age, race, gender, or ethnicity.

In addition, the legislation emphasizes the need for continued biomedical research at the National Institutes of Health on the diagnosis, treatment, and prevention of CHD.

NIH will further research into the causes of congenital heart defects, including genetic causes, and study long-term outcomes in individuals with CHD of all ages. Also, NIH may study data to identify effective treatments and outcomes and identify barriers to lifelong care for individuals with congenital heart defects.

CHD is the most common birth defect and the leading cause of birth defect-related infant mortality. For the Down syndrome community, about half of the children born with Down syndrome have CHD. It is a true public health issue and, as late-night show host Jimmy Kimmel noted, it does not discriminate by race, gender, or socioeconomic status.

The road ahead may be scary and uncertain for any parent with a newborn who has CHD, but this bill helps give hope to those coping with the diagnosis. Nearly 1 in 100 babies are born with CHD, and more than 5 percent will not live to see their first birthday, unfortunately. We have to change that.

Even for those who receive successful intervention, it is not a cure. We have to change that.

Children and adults born with CHD require ongoing, costly, specialized cardiac care and face a lifelong risk of permanent disability and premature death. We must change that.

As a result, healthcare utilization among the CHD population is significantly higher than the general population. It is estimated that, compared to their peers, the medical costs for individuals with congenital heart defects are 10 to 20 times greater.

Hospitalization costs for pediatric patients alone total more than \$5.6 billion each year, which is 15 percent of

all hospitalization costs for patients 20 years of age and younger.

Despite its prevalence and significance, there are still gaps in research and standards of care for CHD patients. But for the sake of the estimated 40,000 babies, Mr. Speaker, who will be born in the next year with CHD, there is more work to be done.

Mr. Speaker, I began this journey almost 10 years ago, when then-Congressman Zack Space and I first introduced the Congenital Heart Futures Act. Last Congress, Congressman SCHIFF and I reintroduced the reauthorization of the original bill. During that time, I met a lot of patients with congenital heart defects along the way, and I have been touched by their stories.

There are people like Trey and Nicole Flynn, a young Floridian couple who lost their son, Holden, while waiting for a heart transplant. He was only 2 years old.

This bill supports the essential research necessary to make sure another family doesn't have to leave the hospital without their child in their arms.

There is also Lucas Iguina, a young man born with a complex congenital heart disease that essentially left him with half a heart.

□ 1730

Despite having three open-heart surgeries, Mr. Speaker, and countless doctor visits and medical procedures, Lucas has hopes and dreams like every other child. This bill ensures that the medical research will keep pace with his generation as they grow to be adults.

The SPEAKER pro tempore. The time of the gentleman has expired.

Mr. BURGESS. Mr. Speaker, I yield an additional 1 minute to the gentleman from Florida.

Mr. BILIRAKIS. Jackson Radandt, born with half a heart, has hypoplastic left heart syndrome, which means the left side of his heart was underdeveloped. He depended on lifesaving research to help his failing heart survive until his heart transplant at age 11. He is a teenager now and will live his life with a heightened sensitivity for his new heart.

Nicholas Basken was born with complex heart disease and wasn't getting blood to the lower half of his body, requiring heart surgery when he was just 2 days old. He is now at the top of his class, and this bill will ensure that his future remains bright as he navigates this chronic illness throughout his adulthood.

Abigail Adams is a young Florida advocate, whom I will meet again tomorrow, with Down syndrome. Roughly half of the babies born with Down syndrome, Mr. Speaker, have a congenital heart defect. Abigail continues to advocate for individuals with Down syndrome.

The SPEAKER pro tempore. The time of the gentleman has again expired.

Mr. BURGESS. Mr. Speaker, I yield an additional 30 seconds to the gentleman from Florida.

Mr. BILIRAKIS. My friend, David Peluso, was born with pulmonary stenosis, a condition where the pulmonary valve will not open properly. He had surgery, again, emergency open-heart surgery, at 2 days old, another corrective surgery at age 10, and many hospital visits and procedures in the meantime.

Today, again, we are giving these children hope. Today, he is a husband and a father to two kids, trying to live a normal life with atrial flutter that requires additional surgeries. This bill will continue the surveillance program so we can collect data on children and adults with congenital heart problems.

I can go on and on, Mr. Speaker. Thank you so very much, and let's pass this great bill for our children and give them hope.

Mr. GENE GREEN of Texas. Mr. Speaker, I have no other speakers.

I want to thank, also, the cosponsors of the bill, both Congressman SCHIFF and a member of our committee, Congressman BILIRAKIS, for introducing this reauthorization bill, and I yield back the balance of my time.

Mr. BURGESS. Mr. Speaker, I yield 1 minute to the gentleman from Georgia (Mr. CARTER).

Mr. CARTER of Georgia. Mr. Speaker, I thank the gentleman for yielding.

Mr. Speaker, I rise today in support of the Congenital Heart Futures Reauthorization Act. This legislation was introduced by the gentleman from Florida (Mr. BILIRAKIS), a colleague and good friend, to address a very serious issue.

Congenital heart disease is the leading cause of infant mortality and is the most common birth defect found in young children. These children grow up facing a wealth of health issues that will have a tremendous impact on them for the rest of their lives. They often require specialized care, including cardiac care, and are subjected to a lifetime of risk for disability or premature death.

This legislation enhances research and surveillance at the CDC to ensure that our medical community and the research to support their efforts are the best available for treatment. It also establishes grants to further study congenital heart disease so that we can better combat this disease and the harm it causes in so many people's lives.

Mr. Speaker, this is a terrible disease that leaves people never knowing when it could strike. Like other diseases, we need to better understand how it develops and impacts people so that we have a better chance of fighting it and saving lives.

I thank my colleagues on both sides of the aisle for getting this legislation passed through the Energy and Commerce Committee, and I support its passage.

Mr. BURGESS. Mr. Speaker, having no further speakers, I yield back the balance of my time.

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. 1222, 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, 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, further proceedings on this motion will be postponed.

#### SICKLE CELL DISEASE RESEARCH, SURVEILLANCE, PREVENTION, AND TREATMENT ACT OF 2017

Mr. BURGESS. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 2410) to amend the Public Health Service Act to reauthorize a sickle cell disease prevention and treatment demonstration program and to provide for sickle cell disease research, surveillance, prevention, and treatment.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 2410

*Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*

#### SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the “Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2017”.

(b) TABLE OF CONTENTS.—The table of contents of this Act is as follows:

- Sec. 1. Short title; table of contents.
- Sec. 2. Sickle cell disease research.
- Sec. 3. Sickle cell disease surveillance.
- Sec. 4. Sickle cell disease prevention and treatment.
- Sec. 5. Collaboration with community-based entities.

#### SEC. 2. SICKLE CELL DISEASE RESEARCH.

Part P of title III of the Public Health Service Act is amended by inserting after section 399V-6 (42 U.S.C. 280g-17) the following:

#### “SEC. 399V-7. NATIONAL SICKLE CELL DISEASE RESEARCH, SURVEILLANCE, PREVENTION, AND TREATMENT PROGRAM.

“(a) RESEARCH.—The Secretary may conduct or support research to expand the understanding of the cause of, and to find a cure for, sickle cell disease.”.

#### SEC. 3. SICKLE CELL DISEASE SURVEILLANCE.

Section 399V-7 of the Public Health Service Act, as added by section 2, is amended by adding at the end the following:

“(b) SURVEILLANCE.—

“(1) GRANTS.—The Secretary may, for each fiscal year for which appropriations are available to carry out this subsection, make grants to not more than 20 States—

“(A) to conduct surveillance and maintain data on the prevalence and distribution of sickle cell disease and its associated health outcomes, complications, and treatments;

“(B) to conduct public health initiatives with respect to sickle cell disease, including—

“(i) increasing efforts to improve access to, and receipt of, high-quality sickle cell disease-related health care, including the use of treatments approved under section 505 of the Federal Food, Drug, and Cosmetic Act or licensed under section 351 of this Act;