And, again, Mr. Speaker, I thank the chairman and Ms. CASTOR for their leadership here.

Mr. BARTON. Mr. Speaker, I yield 1 minute to the gentleman from New York (Mr. ZELDIN).

Mr. ZELDIN. Mr. Speaker, I thank Mr. BARTON for yielding the time.

Mr. Speaker, today I rise to speak in support of language that was added to the IMPROVE Act that would protect access to critical equipment for individuals with disabilities.

In November of 2014, the Centers for Medicare and Medicaid Services issued a rule stating that accessories used on complex rehabilitative wheelchairs would no longer be part of the fixed fee schedule and would be subject to competitive bidding pricing, decreasing access to customized wheelchairs and accessories relied on by adults and children with disabilities.

My language included in this legislation will include a commonsense clarification to ensure those in the Medicare Program do not have to go through the difficulty of adjusting to the new rules and pricing arbitrarily set by CMS. This will ensure that they have reliable and consistent access to the equipment they need.

Mr. Speaker, I urge my colleagues to protect those with disabilities and their access to the resources they rely on.

Mr. BARTON. Mr. Speaker, may I inquire how much time I have remaining?

The SPEAKER pro tempore. The gentleman from Texas has 2½ minutes remaining.

Mr. BARTON. Mr. Speaker, I yield myself the balance of my time.

Mr. Speaker, before I close, I want to set the record straight on one thing. There has been a report that this bill, the ACE Kids Act, expands Medicaid. That is factually incorrect.

The children that qualify for the ACE Kids Act are already covered by Medicaid.

There is no expansion. We do not create a new program. We do not expand an existing program. We do not change the definitions.

We simply make it possible, if this bill becomes law, for parents of children that qualify and that are already covered under Medicaid, they can choose a healthcare home for their child, and that healthcare home can cross State lines. But as Dr. BURGESS pointed out, it is not coercive. The States don't have to participate in the program, the families don't have to participate in the program. It is all voluntary. But the pilot programs that have been done on this model, they save money and they give better care. It has been proven.

CBO has scored this over time that it saves money, but we put pay-fors in the bill. If it did cost some extra money, it would be paid for. There is a 2-quarter, 6-month increase in the FMAP, the Federal matching that the Federal Government gives to States that choose to participate. I think it is about 15 percent extra money for 6 months. That is the only cost.

Now, to close, I am going to read a list, and Congresswoman CASTOR read a lot of these, but these are the national groups that support our bill: the Adult Congenital Heart Association, America's Essential Hospitals, American Academy of Pediatrics, American Association of Child & Adolescent Psychiatry, American Board of Pediatrics, American College of Cardiology, American College of Surgeons, American Heart Association, American Psychological Association, American Society of Echocardiography, American Thoracic Society, Amicus Therapeutics, Association of American Medical Colleges, Association of Medical School Pediatric Department Chairs, Autism Society, Autism Speaks, ChildServe, Children's Cause for Cancer Advocacy, Children's Hospital Association, Epilepsy Foundation, Family Voices, Foundation to Eradicate Duchenne, International Pediatric Rehabilitation Collaborative, March of Dimes, Mended Little Hearts, MomsRising, National Association for Children's Behavioral Health. There are about seven or ten more.

Mr. Speaker, I want to thank the staff, especially Krista Rosenthall, Jeannine Bender, committee staff Caleb Graff, Josh Trent, and Ryan Long. And, again, I thank KATHY CASTOR and GENE GREEN.

Mr. Speaker, this has been a bipartisan effort. I ask for a strong ''yea'' vote.

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

Mr. SMITH of Texas. Mr. Speaker, I believe it is important to make very clear with this legislation that CMS should not waive any Medicaid state plan requirements that would limit the freedom to choose qualified Medicaid providers who can provide medical services to children with chronic conditions. Nothing in this bill modifies section 1902(a)(23) of the Social Security Act—related to freedom of choice requirements. Children and their families or guardians retain the right to elect care from a provider or supplier who is qualified and eligible to receive Medicaid payment for the services. It is the intent of this legislation to permit and guarantee the family, in consultation with their physician, in all instances, to be permitted to select the best provider/supplier who can meet the patient's needs. While I support this legislation to provide care coordination for these children, the ultimate choice of the who will provide direct medical services must remain with the family.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from Texas (Mr. BARTON) that the House suspend the rules and pass the bill, H.R. 7217.

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. BARTON. 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 AND OTHER HERITABLE BLOOD DISORDERS RESEARCH, SURVEILLANCE, PREVENTION, AND TREATMENT ACT OF 2018

Mr. BURGESS. Mr. Speaker, I move to suspend the rules and pass the bill (S. 2465) 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:

S. 2465

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 ''Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018''.

SEC. 2. DATA COLLECTION ON CERTAIN BLOOD DISORDERS.

Part A of title XI of the Public Health Service Act is amended by inserting after section 1105 (42 U.S.C. 300b–4) the following:

''SEC. 1106. SICKLE CELL DISEASE AND OTHER HERITABLE BLOOD DISORDERS RESEARCH, SURVEILLANCE, PREVENTION, AND TREATMENT.

''(a) GRANTS.—

''(1) IN GENERAL.—The Secretary may award grants related to heritable blood disorders, including sickle cell disease, for one or more of the following purposes:

''(A) To collect and maintain data on such diseases and conditions, including subtypes as applicable, and their associated health outcomes and complications, including for the purpose of—

''(i) improving national incidence and prevalence data;

''(ii) identifying health disparities, including the geographic distribution, related to such diseases and conditions;

''(iii) assessing the utilization of therapies and strategies to prevent complications; and

''(iv) evaluating the effects of genetic, environmental, behavioral, and other risk factors that may affect such individuals.

''(B) To conduct public health activities with respect to such conditions, which may include—

''(i) developing strategies to improve health outcomes and access to quality health care for the screening for, and treatment and management of, such diseases and conditions, including through public-private partnerships;

''(ii) providing support to community-based organizations and State and local health departments in conducting education and training activities for patients, communities, and health care providers concerning such diseases and conditions;

''(iii) supporting State health departments and regional laboratories, including through training, in testing to identify such diseases and conditions, including specific forms of sickle cell disease, in individuals of all ages; and

''(iv) the identification and evaluation of best practices for treatment of such diseases and conditions, and prevention and management of their related complications.

''(2) POPULATION INCLUDED.—The Secretary shall, to the extent practicable, award grants

under this subsection to eligible entities across the United States to improve data on the incidence and prevalence of heritable blood disorders, including sickle cell disease, and the geographic distribution of such diseases and conditions.

''(3) APPLICATION.—To seek a grant under this subsection, an eligible entity shall submit an application to the Secretary at such time, in such manner, and containing such information as the Secretary may require.

''(4) PRIORITY.—In awarding grants under this subsection, the Secretary may give priority, as appropriate, to eligible entities that have a relationship with a community-based organization that has experience in, or is capable of, providing services to individuals with heritable blood disorders, including sickle cell disease.

''(5) ELIGIBLE ENTITY.—In this subsection, the term 'eligible entity' includes the 50 States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, the Commonwealth of the Northern Mariana Islands, American Samoa, Guam, the Federated States of Micronesia, the Republic of Marshall Islands, the Republic of Palau, Indian tribes, a State or local health department, an institution of higher education, or a nonprofit entity with appropriate experience to conduct the activities under this subsection.''.

SEC. 3. SICKLE CELL DISEASE PREVENTION AND TREATMENT.

(a) REAUTHORIZATION.—Section 712(c) of the American Jobs Creation Act of 2004 (Public Law 108–357; 42 U.S.C. 300b–1 note) is amended—

(1) by striking ''Sickle Cell Disease'' each place it appears and inserting ''sickle cell disease'';

(2) in paragraph (1)(A), by striking ''shall conduct a demonstration program by making grants to up to 40 eligible entities for each fiscal year in which the program is conducted under this section for the purpose of developing and establishing systemic mechanisms to improve the prevention and treatment of Sickle Cell Disease'' and inserting ''shall continue efforts, including by awarding grants, to develop or establish mechanisms to improve the treatment of sickle cell disease, and to improve the prevention and treatment of complications of sickle cell disease, in populations with a high proportion of individuals with sickle cell disease'';

(3) in paragraph (1)(B)—

(A) by striking clause (ii) (relating to priority); and

(B) by striking ''GRANT AWARD REQUIREMENTS'' and all that follows through ''The Administrator shall'' and inserting ''GEOGRAPHIC DIVERSITY.—The Administrator shall'';

(4) in paragraph (2), by adding the following new subparagraph at the end:

''(E) To provide or coordinate services for adolescents with sickle cell disease making the transition to adult health care.''; and

(5) in paragraph (6), by striking ''$10,000,000 for each of fiscal years 2005 through 2009'' and inserting ''$4,455,000 for each of fiscal years 2019 through 2023''.

(b) TECHNICAL CHANGES.—Subsection (c) of section 712 of the American Jobs Creation Act of 2004 (Public Law 108–357; 42 U.S.C. 300b–1 note), as amended by subsection (a), is—

(1) transferred to the Public Health Service Act (42 U.S.C. 201 et seq.);

(2) redesignated as subsection (b); and

(3) inserted at the end of section 1106 of such Act, as added by section 2 of this Act.

SEC. 4. SENSE OF THE SENATE.

It is the Sense of the Senate that further research should be undertaken to expand the understanding of the causes of, and to find cures for, heritable blood disorders, including sickle cell disease.

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 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, I rise to speak in support of S. 2465, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018.

The policy included in this legislation is something on which Congress has been working towards for years, as improvements for individuals with sickle cell have largely remained stagnant.

This text is similar to H.R. 2410, which was introduced by Representative DANNY DAVIS and myself and passed this Chamber unanimously in February.

Mr. Speaker, I would like to thank Representative DAVIS, in addition to Senator TIM SCOTT and Senator CORY BOOKER for working with me on this important policy.

Since the passage of the Sickle Cell Anemia Control Act of 1972, the first law to address sickle cell, individuals living with this disease have seen a substantial drop in mortality rates; however, there remains work to be done.

According to the Centers for Disease Control and Prevention, there are approximately 100,000 individuals in the United States with sickle cell. Additionally, the disease occurs in 1 in 365 African American births, and in 1 in 13 African American births, the newborn has the sickle cell trait.

In the 1990s, the Food and Drug Administration approved hydroxyurea, which stimulates the body to resume production of fetal hemoglobin to treat sickle cell disease.

Last year the Food and Drug Administration approved Endari, which was the first new approved treatment in over 20 years.

I met with Dr. Janet Woodcock and Dr. Peter Marks to learn more about why the approvals have taken such a long time.

This bill would further our commitment to helping those with sickle cell by both continuing the Health Resources and Service Administration's Sickle Cell Disease Prevention and Treatment Demonstration Program and by allowing the Centers for Disease Control and Prevention to conduct surveillance of the disease and other heritable blood disorders.

The CDC's surveillance activity will allow for identification of health disparities, analysis of utilization of existing therapies, and evaluation of genetic, environmental, behavioral, and other risk factors.

Having worked with patients with sickle cell disease while at Parkland Hospital, I have seen firsthand the real consequences that this disease can have on people.

This bill provides an important step forward in ensuring that we have the resources to better understand this illness and maintain access for services for those affected by the disease.

While sickle cell disease has been addressed in bills like the 21st Century Cures Act, among other rare diseases, it has been a long time since this illness was substantially addressed in legislation.

The future of sickle cell disease treatment is bright if we pass this legislation and send it to President Trump. Better understanding of the landscape of sickle cell disease across the Nation and investing in new research for new treatments holds much promise for individuals and families who spend every day managing their disease.

Think of the children who have been unable to play or had to quit competing, or who have had to struggle through school because they are frequently absent due to the complications or pain from their underlying sickle cell illness.

The support this bill provides will enable public-private partnerships to take the reins to fight this disease head-on in communities across the country.

Mr. Speaker, I urge Members to support this legislation so we can send it promptly to the President's desk.

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

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

Mr. Speaker, I rise in support of S. 2465, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act.

This legislation will reauthorize the Sickle Cell Disease Treatment Demonstration Program at HRSA. This program enhances the prevention and treatment of sickle cell through coordination of service delivery, genetic counseling, testing, training of health professionals, and other related efforts.

The program is particularly important since individuals with sickle cell disease need comprehensive treatment throughout their lives in order to manage their symptoms and prevent their disease from worsening.

Over 100,000 Americans are living with sickle cell disease today. Each will need access to robust network providers with the knowledge and skills to treat this condition.

This is especially important now, for far too many individuals with sickle cell are unable to get the care they need, particularly those who present at emergency departments with intense pain associated with a sickle cell crisis.

In addition to reauthorizing that program, this bill would expand the activities related to sickle cell and other heritable blood disorders by strengthening surveillance and other public health efforts as well as encouraging more research into these health conditions.

Mr. Speaker, I would like to thank Representative DANNY DAVIS, Representative G.K. BUTTERFIELD, and Representative BURGESS for their leadership on this issue.

Mr. Speaker, I urge my colleagues to support S. 2465, which will allow HHS to invest critical resources into research, surveillance, and public health initiatives of sickle cell disease as well as other heritable blood disorders. These investments will help bolster the sickle cell workforce and improve treatments for sickle cell patients of all ages.

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

□ 1330

Mr. BURGESS. Mr. Speaker, I yield 2 minutes 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 S. 2465, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act.

This legislation, which has been sponsored by Senator SCOTT, makes important updates to statute so as to better help our medical professionals understand and treat sickle cell and other blood disorders.

Sickle cell is a terrible disease, inflicting extremely difficult effects on those who have this condition. Today's legislation will allow us to move forward and combat this and other heritable blood disorders so that we can provide a better quality of life to those who suffer from them.

We are very fortunate to have some world-class treatment options in my home State of Georgia at health systems like Emory University. They are doing incredible work in treating and understanding this disease so that we can improve the lives of all who suffer from these forms of diseases.

This legislation supports State health departments, establishes best practices, improves data collection efforts, and develops strategies that will hopefully allow us to eventually fully address these diseases.

Mr. Speaker, I thank my colleagues for their work on this, and I urge them to support this legislation.

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

Mr. BURGESS. Mr. Speaker, I yield myself the balance of my time.

I want to point out, Mr. Speaker, that this bill we are passing today has already passed the Senate. While we did work on a similar bill well over a year ago, this bill has passed the Senate. With our passage today, this bill goes down the street to the White House for signature to become law: the first major sickle cell bill to be enacted in quite some time.

It is a banner day for this institution that we are providing this help to citizens, fundamentally, on this very crucial problem that affects so many of our fellow citizens.

Mr. Speaker, I urge all Members to vote in favor of this bill, and I yield back the balance of my time.

Mr. BUTTERFIELD. Mr. Speaker, I rise today to express my support for H.R. 2410, the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2017, that passed the U.S. House of Representatives on February 26, 2018. Today, the House of Representatives passed S. 2465, which is the Senate-amended version of H.R. 2410. As a co-sponsor of H.R. 2410 and the immediate past Chair of the Congressional Black Caucus, I rise to clarify the Congressional intent of this important legislation.

I commend my friends, Representative DANNY DAVIS from Illinois and Representative MICHAEL BURGESS from Texas, for introducing H.R. 2410. I have been a longtime advocate for those with sickle cell disease and I am a proud co-sponsor of the bill in this Congress and in previous Congresses.

There are approximately forty-four hundred people with sickle cell disease in my home state of North Carolina. My hope is that someday there will be none. Sixty-five percent of individuals with sickle cell disease in North Carolina have at least one emergency room visit per year—that is no way to live. We should do all we can to help improve patients' lives, advance treatment, and find a cure.

That is why we must reauthorize the Sickle Cell Disease Treatment Demonstration Program to enable the Secretary of the Department of Health and Human Services to support research that will increase our understanding of sickle cell disease, and create a grant program to study the prevalence of sickle cell and identify ways to prevent and treat sickle cell disease effectively.

S. 2465 makes changes to the House-approved language that warrant clarification Notably, Sec. 2 of S. 2465 enables the awarding of grants related to heritable blood disorders, including sickle cell disease, for the purposes of research, surveillance, prevention, and treatment. It is imperative to stress that the intent of this language is to require that those grants be awarded for sickle cell disease research, surveillance, prevention, and treatment, at minimum. It is not the intent of the language for grants to be awarded related to other heritable blood disorders (e.g. hemophilia) instead of or in lieu of sickle cell disease.

Finally, Sec. 3 of S. 2465, reauthorizing the Sickle Cell Disease Treatment Demonstration Program, is intended to provide awards related only to sickle cell disease. It is not the intent of the legislation to allocate awards made under Sec. 3 for other heritable diseases.

Mr. Speaker, this legislation is intended to provide critical funding to assist those with sickle cell disease, and any awards made under Sec. 2 or Sec. 3 of this bill must be used for sickle cell disease response.

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, S. 2465.

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

A motion to reconsider was laid on the table.

PREMATURITY RESEARCH EXPANSION AND EDUCATION FOR MOTHERS WHO DELIVER INFANTS EARLY REAUTHORIZATION ACT OF 2018

Mr. BURGESS. Mr. Speaker, I move to suspend the rules and pass the bill (S. 3029) to revise and extend the Prematurity Research Expansion and Education for Mothers who deliver Infants Early Act (PREEMIE Act).

The Clerk read the title of the bill.

The text of the bill is as follows:

S. 3029

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 ''Prematurity Research Expansion and Education for Mothers who deliver Infants Early Reauthorization Act of 2018'' or the ''PREEMIE Reauthorization Act of 2018''.

SEC. 2. RESEARCH RELATING TO PRETERM LABOR AND DELIVERY AND THE CARE, TREATMENT, AND OUTCOMES OF PRETERM AND LOW BIRTHWEIGHT INFANTS.

Section 2 of the Prematurity Research Expansion and Education for Mothers who deliver Infants Early Act (42 U.S.C. 247b–4f) is amended—

(1) in subsection (b)—

(A) in paragraph (1)(A), by striking ''clinical, biological, social, environmental, genetic, and behavioral factors relating'' and inserting ''factors relating to prematurity, such as clinical, biological, social, environmental, genetic, and behavioral factors, and other determinants that contribute to health disparities and are related''; and

(B) in paragraph (2), by striking '' concerning the progress and any results of studies conducted under paragraph (1)'' and inserting ''regarding activities and studies conducted under paragraph (1), including any applicable analyses of preterm birth. Such report shall be posted on the Internet website of the Department of Health and Human Services.'';

(2) by striking subsection (c) and inserting the following:

''(c) PREGNANCY RISK ASSESSMENT MONITORING SURVEY.—The Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, shall—

''(1) continue systems for the collection of maternal-infant clinical and biomedical information, including electronic health records, electronic databases, and biobanks, to link with the Pregnancy Risk Assessment Monitoring System (PRAMS) and other epidemiological studies of prematurity in order to track, to the extent practicable, all pregnancy outcomes and prevent preterm birth; and