

factors of sickle cell disease, especially for the data collection part, which is the heart of the surveillance program in the law. This law expired in late 2023.

H.R. 3884, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023, is a bipartisan bill by Representatives Dr. MICHAEL BURGESS; myself, DANNY DAVIS; Representative BUDDY CARTER; and BARBARA LEE. It is a companion bill to the Senate version S. 1852 by Senators TIM SCOTT, CORY BOOKER, and RAPHAEL WARNOCK.

H.R. 3884 would extend the reauthorization of the sickle cell disease treatment demonstration program through FY 2028 that supports efforts to improve treatment, reduce risk and complications, and cure this disease.

Mr. Speaker, I urge all of my colleagues to vote "yes."

Mr. BUCSHON. Mr. Speaker, I yield 5 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 strong support of the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act.

As a pharmacist for over four decades, I have seen firsthand the heart-breaking toll sickle cell disease takes on patients and their families.

Sickle cell disease is a destructive disease, attacking red blood cells in the body and causing patients strong episodes of pain over time.

Unfortunately, Georgia is home to one of the largest sickle cell disease populations in the country, which is why it is so important that we act quickly to save lives and prevent further pain.

The bill before us today reauthorizes critical sickle cell disease programs so that patients have the support and resources they need to battle this terrible disease. I have always and will always commit to putting patients first, and I believe these programs do just that.

Mr. Speaker, I thank Dr. BURGESS for working on this important issue, and I urge my colleagues to support this legislation.

Mr. BUCSHON. Mr. Speaker, I have no further speakers, I am prepared to close, and I reserve the balance of my time.

Mr. PALLONE. Mr. Speaker, again, I urge that we support this legislation on a bipartisan basis. Sickle cell disease is something that we need to continue to research and help with. This is an important bill in that respect.

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

Mr. BUCSHON. Mr. Speaker, in closing, I encourage a "yes" vote on the bill, and I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by

the gentleman from Indiana (Mr. BUCSHON) that the House suspend the rules and pass the bill, H.R. 3884, 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.

CHARLOTTE WOODWARD ORGAN TRANSPLANT DISCRIMINATION PREVENTION ACT

Mr. BUCSHON. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 2706) to prohibit discrimination on the basis of mental or physical disability in cases of organ transplants, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 2706

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 "Charlotte Woodward Organ Transplant Discrimination Prevention Act".

SEC. 2. DEFINITIONS.

In this Act:

(1) **AUXILIARY AIDS AND SERVICES.**—The term "auxiliary aids and services" has the meaning given the term in section 4 of the Americans with Disabilities Act of 1990 (42 U.S.C. 12103).

(2) **COVERED ENTITY.**—The term "covered entity" means any licensed provider of health care services (including licensed health care practitioners, hospitals, nursing facilities, laboratories, intermediate care facilities, psychiatric residential treatment facilities, institutions for individuals with intellectual or developmental disabilities, and prison health centers), and any transplant hospital (as defined in section 121.2 of title 42, Code of Federal Regulations or a successor regulation), that—

(A) is in interstate commerce; or

(B) provides health care services in a manner that—

(i) substantially affects or has a substantial relation to interstate commerce; or

(ii) includes use of an instrument (including an instrument of transportation or communication) of interstate commerce.

(3) **DISABILITY.**—The term "disability" has the meaning given the term in section 3 of the Americans with Disabilities Act of 1990 (42 U.S.C. 12102).

(4) **HUMAN ORGAN.**—The term "human organ" has the meaning given the term in section 301(c) of the National Organ Transplant Act (42 U.S.C. 274e(c)).

(5) **ORGAN TRANSPLANT.**—The term "organ transplant" means the transplantation or transfusion of a donated human organ into the body of another human for the purpose of treating a medical condition.

(6) **QUALIFIED INDIVIDUAL.**—The term "qualified individual" means an individual who, with or without a support network, provision of auxiliary aids and services, or reasonable modifications to policies or practices, meets eligibility requirements for the receipt of a human organ.

(7) **REASONABLE MODIFICATIONS TO POLICIES OR PRACTICES.**—The term "reasonable modifications to policies or practices" includes—

(A) communication with persons responsible for supporting a qualified individual with post-surgical or other care following an organ transplant or related services, including support with medication;

(B) consideration, in determining whether a qualified individual will be able to comply with

health requirements following an organ transplant or receipt of related services, of support networks available to the qualified individual, including family, friends, and providers of home and community-based services, including home and community-based services funded through the Medicare or Medicaid program under title XVIII or XIX, respectively, of the Social Security Act (42 U.S.C. 1395 et seq., 1396 et seq.), another health plan in which the qualified individual is enrolled, or any program or source of funding available to the qualified individual; and

(C) the use of supported decision-making, when needed, by a qualified individual.

(8) **RELATED SERVICES.**—The term "related services" means services related to an organ transplant that consist of—

(A) evaluation;

(B) counseling;

(C) treatment, including postoperative treatment, and care;

(D) provision of information; and

(E) any other service recommended or required by a physician.

(9) **SUPPORTED DECISION-MAKING.**—The term "supported decision-making" means the use of a support person to assist a qualified individual in making health care decisions, communicate information to the qualified individual, or ascertain a qualified individual's wishes. Such term includes—

(A) the inclusion of the individual's attorney-in-fact or health care proxy, or any person of the individual's choice, in communications about the individual's health care;

(B) permitting the individual to designate a person of the individual's choice for the purposes of supporting that individual in communicating, processing information, or making health care decisions;

(C) providing auxiliary aids and services to facilitate the individual's ability to communicate and process health-related information, including providing use of assistive communication technology;

(D) providing health information to persons designated by the individual, consistent with the regulations promulgated under section 264(c) of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d-2 note) and other applicable laws and regulations governing disclosure of health information;

(E) providing health information in a format that is readily understandable by the individual; and

(F) working with a court-appointed guardian or other person responsible for making health care decisions on behalf of the individual, to ensure that the individual is included in decisions involving the health care of the individual and that health care decisions are in accordance with the individual's own expressed interests.

(10) **SUPPORT NETWORK.**—The term "support network" means, with respect to a qualified individual, one or more people who are—

(A) selected by the qualified individual or by the qualified individual and the guardian of the qualified individual, to provide assistance to the qualified individual or guidance to that qualified individual in understanding issues, making plans for the future, or making complex decisions; and

(B) who may include the family members, friends, unpaid supporters, members of the religious congregation, and appropriate personnel at a community center, of or serving the qualified individual.

SEC. 3. PROHIBITION OF DISCRIMINATORY POLICY.

The board of directors described in section 372(b)(1)(B) of the Public Health Service Act (42 U.S.C. 274(b)(1)(B)) shall not issue policies, recommendations, or other memoranda that would prohibit, or otherwise hinder, a qualified individual's access to an organ transplant solely on the basis of that individual's disability.

SEC. 4. PROHIBITION OF DISCRIMINATION.

(a) *IN GENERAL.*—Subject to subsection (b), a covered entity may not, solely on the basis of a qualified individual's disability—

(1) determine that the individual is ineligible to receive an organ transplant or related services;

(2) deny the individual an organ transplant or related services;

(3) refuse to refer the individual to an organ transplant center or other related specialist for the purpose of receipt of an organ transplant or other related services; or

(4) refuse to place the individual on an organ transplant waiting list.

(b) *EXCEPTION.*—

(1) *IN GENERAL.*—

(A) *MEDICALLY SIGNIFICANT DISABILITIES.*—Notwithstanding subsection (a), a covered entity may take a qualified individual's disability into account when making a health care treatment or coverage recommendation or decision, solely to the extent that the disability has been found by a physician, following an individualized evaluation of the potential recipient, to be medically significant to the receipt of the organ transplant or related services, as the case may be.

(B) *CONSTRUCTION.*—Subparagraph (A) shall not be construed to require a referral or recommendation for, or the performance of, a medically inappropriate organ transplant or medically inappropriate related services.

(2) *CLARIFICATION.*—If a qualified individual has the necessary support network to provide a reasonable assurance that the qualified individual will be able to comply with health requirements following an organ transplant or receipt of related services, as the case may be, the qualified individual's inability to independently comply with those requirements may not be construed to be medically significant for purposes of paragraph (1).

(c) *REASONABLE MODIFICATIONS.*—A covered entity shall make reasonable modifications to policies or practices (including procedures) of such entity if such modifications are necessary to make an organ transplant or related services available to qualified individuals with disabilities, unless the entity can demonstrate that making such modifications would fundamentally alter the nature of such policies or practices.

(d) *CLARIFICATIONS.*—

(1) *NO DENIAL OF SERVICES BECAUSE OF ABSENCE OF AUXILIARY AIDS AND SERVICES.*—For purposes of this section, a covered entity shall take such steps as may be necessary to ensure that a qualified individual with a disability is not denied a procedure associated with the receipt of an organ transplant or related services, because of the absence of auxiliary aids and services, unless the covered entity can demonstrate that taking such steps would fundamentally alter the nature of the procedure being offered or would result in an undue burden on the entity.

(2) *COMPLIANCE WITH OTHER LAW.*—Nothing in this section shall be construed—

(A) to prevent a covered entity from providing organ transplants or related services at a level that is greater than the level that is required by this section; or

(B) to limit the rights of an individual with a disability under, or to replace or limit the scope of obligations imposed by, the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.) including the provisions added to such Act by the ADA Amendments Act of 2008, section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), section 1557 of the Patient Protection and Affordable Care Act (42 U.S.C. 18116), or any other applicable law.

(e) *ENFORCEMENT.*—

(1) *IN GENERAL.*—Any individual who alleges that a qualified individual was subject to a violation of this section by a covered entity may bring a claim regarding the allegation to the Of-

fice for Civil Rights of the Department of Health and Human Services, for expedited resolution, as appropriate.

(2) *RULE OF CONSTRUCTION.*—Nothing in this subsection is intended to limit or replace available remedies under the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.) or any other applicable law.

SEC. 5. APPLICATION TO EACH PART OF PROCESS.

The provisions of this Act—

(1) that apply to an organ transplant, also apply to the evaluation and listing of a qualified individual, and to the organ transplant and post-organ-transplant treatment of such an individual; and

(2) that apply to related services, also apply to the process for receipt of related services by such an individual.

SEC. 6. EFFECT ON OTHER LAWS.

Nothing in this Act shall be construed to supersede any provision of any State or local law that provides greater rights to qualified individuals with respect to organ transplants than the rights established under this Act.

The SPEAKER pro tempore. Pursuant to the rule, the gentleman from Indiana (Mr. BUCSHON) and the gentleman from New Jersey (Mr. PALLONE) each will control 20 minutes.

The Chair recognizes the gentleman from Indiana.

GENERAL LEAVE

Mr. BUCSHON. Mr. 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 in the RECORD on the bill.

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

There was no objection.

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

Mr. Speaker, I rise in support of H.R. 2760, the Charlotte Woodward Organ Transplant Discrimination Prevention Act, led by Representative CAMMACK.

This bill prohibits covered entities from determining that an individual is ineligible to receive a transplant or denying a transplant based solely on the fact that the individual has a disability.

H.R. 2706 will clarify that organ transplant discrimination on the basis of disability is prohibited and require the HHS Office of Civil Rights to review these claims in an expedited manner to ensure a timely resolution.

There have been too many instances in which individuals with disabilities have been denied a lifesaving organ transplant, and this is unacceptable.

Congress has the opportunity to help ensure individuals with disabilities are treated fairly within the organ transplant system.

No one should be denied access to an organ transplant just because they have a disability.

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

□ 1530

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

Mr. Speaker, I rise in support of H.R. 2706, the Charlotte Woodward Organ

Transplant Discrimination Prevention Act.

Mr. Speaker, this bill prohibits eligible individuals from being denied a life-saving organ transplant based solely on their disability status. Existing Federal laws, including the Americans with Disabilities Act, the Rehabilitation Act, and the Affordable Care Act, already prohibit organ transplant centers from discriminating based solely on disability.

However, there are still cases where people with disabilities have been denied access to organ transplants. This is often because of misperceptions about how a disability impacts the medical likelihood of transplant success or unfounded assumptions regarding disabled persons' abilities to comply with postoperative care.

This bill prohibits covered entities from determining that an individual is ineligible to receive a transplant based solely on the fact that the individual has a disability. It also acknowledges the importance of support networks and services and helping with postoperative care.

Mr. Speaker, organ transplants can save lives, and it is important that the system be free from discrimination. I am glad that we are taking this step to clarify and build upon existing civil rights protections for people with disabilities. I thank our colleagues on the Energy and Commerce Committee, Mrs. CAMMACK and Representative DINGELL, as well, for their bipartisan work on this bill.

Mr. Speaker, I encourage all my colleagues to vote "yes" on H.R. 2706, and I reserve the balance of my time.

Mr. BUCSHON. Mr. Speaker, I yield 5 minutes to the gentlewoman from Florida (Mrs. CAMMACK).

Mrs. CAMMACK. Mr. Speaker, I thank my colleague, Representative BUCSHON, for yielding me time.

Mr. Speaker, it is an honor to stand here today and debate H.R. 2706, the Charlotte Woodward Organ Transplant Discrimination Prevention Act. Of course, I don't think there is a whole lot of debate that is going to happen here today because I hope it will be unanimous.

For Members who don't know, this bill is named after Charlotte Woodward, an adult woman with Down syndrome who received a lifesaving heart transplant over 12 years ago.

Sadly, as has been mentioned, not all individuals with disabilities have that same opportunity. That is why we are here to consider this bill today, to ensure that all Americans, regardless of the disability they may have, have the same opportunity to receive a life-saving organ transplant.

When I first learned of this issue, I could not believe that this practice was happening here in our country. However, after learning more about the issue and hearing stories from advocates, including Charlotte herself, they were advocating for change. I was shocked and horrified to learn that

there were no protections for these individuals.

According to a 2019 report from the National Council on Disability, which is the agency that advises the legislative and executive branch on disability policy issues, people with disabilities have been routinely denied due to subjective judgments about the value of a human who happens to have a disability, subjective assumptions about their quality of life, and misconceptions about their ability to comply with postoperative care.

Even more, that same report found that some organ transplant programs have policies that exclude, rather than include, people with disabilities as candidates for transplant.

In 2021, as a freshman Member of Congress, I met Bobbi and Josh Sarmiento. They are from Ocala, Florida, in my district. These constituents reached out and wanted to share the story of their son, baby Zion. I spent time learning about their journey and couldn't help being moved to action as I left them that day.

I couldn't possibly do justice in recounting their story. Instead, I will read an excerpt from baby Zion's mom, Bobbi, in her own words, their story and experience with the organ transplant system that she provided to a congressional panel just last year.

In Bobbi's words, she said:

We learned at 10 weeks gestation that our son, Zion, had Down syndrome, and at his 20-week anatomy scan, he had a heart defect called a complete AVSD, or also called a complete AV canal defect. Simply put, we have four chambers in our heart. Zion had a large hole in the center separating those chambers from forming. This is a common heart defect those with Down syndrome have.

Our beautiful boy was born on June 15, 2021. We spent 40 days in the NICU before being discharged to go home. We have some of the best memories of our time at home before his open-heart surgery was scheduled for September of 2021. We did all the research and asked all the questions. We never knew we would end up being the worst-case scenario.

To make a long story short, Zion had 5 open-heart surgeries in a matter of 12 days. He was such a warrior through each one. After the fifth surgery didn't work as planned, we were told that he would need a heart transplant. The hospital we were at did not do transplants, so we were left with three options in Florida. To qualify, we were told his other organs had to be working, which they were, and we have the autopsy to prove this.

Our first option told us that they had never done a successful heart transplant on someone with Down syndrome. I asked how many they had tried. No response. Through my own research and digging that moms do to get answers, I have since learned that the answer was zero. Our second option said that they didn't feel their team could do a successful heart transplant for Zion, and the third option kept us waiting.

Finally, they came back and said that, because baby Zion was on ECMO life support three times through the five surgeries, he couldn't have brain activity. I would like to note that Zion came off ECMO after the second and fifth surgery, which we knew upfront was vital to being accepted for the

heart transplant list. They wanted a brain activity test run and sent to them for their final decision. We were told before it was sent that the test was perfect.

With nothing to disqualify him, we thought that we would be on our way to the next step. They came back and told us that after much deliberation, they concluded that they just couldn't waste a heart.

Wow, that is hard to read.

Our son was worth the same chance at life as anyone else. With no options left, we had to make the decision to remove the machines. On October 8, 2021, our son left our arms and ran into the arms of Jesus.

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

Mr. BUCSHON. Mr. Speaker, I yield such time as she may consume to the gentlewoman from Florida.

Mrs. CAMMACK. Baby Zion deserved the same chance at life as any other American, but he was denied a heart transplant by the same doctors because he had Down syndrome, and they "couldn't waste a heart."

The tragic story of baby Zion and the courage of his parents, Josh and Bobbi, along with the drive of so many incredible advocates, have led us today to H.R. 2706, the Charlotte Woodward Organ Transplant Discrimination Prevention Act, which would prohibit healthcare providers and other entities from denying or restricting an individual's access to organ transplants solely based on an individual's disability.

The bill would require expedited review of discrimination claims at the Office for Civil Rights at the Department of Health and Human Services. No family should have to wait or be denied.

I thank Charlotte Woodward, Bobbi and Josh, and all of the advocates who have worked so hard to get this bill where it is today. We would not be here without your tireless work to educate and advocate on behalf of individuals with disabilities across the country.

I also want to thank my colleague, DEBBIE DINGELL, for her partnership and work on this bill. It was truly an honor to work with the gentlewoman on important issues like this.

I also acknowledge my Senate counterpart, Senator RUBIO, for championing this issue in the Senate.

Lastly, I thank Chair CATHY MCMORRIS RODGERS for her work and support on this issue. Her leadership in Energy and Commerce on this issue and the multitude of important issues that we deal with in the committee cannot be overstated. Not only is the gentlewoman a trailblazer and an ability advocate, but a force of nature.

Mr. Speaker, I urge my colleagues to support this bill.

Mr. BUCSHON. Mr. Speaker, I have no further speakers, and I am prepared to close. I reserve the balance of my time.

Mr. PALLONE. Mr. Speaker, in closing, I think Mrs. CAMMACK explained very well why we need to pass this bill, and I would ask all of my colleagues to support it.

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

Mr. BUCSHON. Mr. Speaker, in closing, I encourage a "yes" vote on this bill, and I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from Indiana (Mr. BUCSHON) that the House suspend the rules and pass the bill, H.R. 2706, 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.

GIVE KIDS A CHANCE ACT OF 2024

Mr. BUCSHON. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 3433) to amend the Federal Food, Drug, and Cosmetic Act with respect to molecularly targeted pediatric cancer investigations, and for other purposes, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 3433

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 "Give Kids a Chance Act of 2024".

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

Sec. 1. Short title; table of contents.

TITLE I—GIVE KIDS A CHANCE

Sec. 101. Research into pediatric uses of drugs; additional authorities of Food and Drug Administration regarding molecularly targeted cancer drugs.

Sec. 102. Ensuring completion of pediatric study requirements.

Sec. 103. FDA report on PREA enforcement.

Sec. 104. Extension of authority to issue priority review vouchers to encourage treatments for rare pediatric diseases.

Sec. 105. Limitations on exclusive approval or licensure of orphan drugs.

Sec. 106. Program for pediatric studies of drugs.

TITLE II—UNITED STATES-ABRAHAM ACCORDS COOPERATION AND SECURITY

Sec. 201. Establishment of Abraham Accords Office within Food and Drug Administration.

TITLE III—ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK

Sec. 301. Registration fees.

TITLE I—GIVE KIDS A CHANCE

SEC. 101. RESEARCH INTO PEDIATRIC USES OF DRUGS; ADDITIONAL AUTHORITIES OF FOOD AND DRUG ADMINISTRATION REGARDING MOLECULARLY TARGETED CANCER DRUGS.

(a) IN GENERAL.—

(1) ADDITIONAL ACTIVE INGREDIENT FOR APPLICATION DRUG; LIMITATION REGARDING NOVEL-COMBINATION APPLICATION DRUG.—Section 505B(a)(3) of the Federal Food, Drug, and Cosmetic Act (21 U.S.C. 355c(a)(3)) is amended—

(A) by redesignating subparagraphs (B) and (C) as subparagraphs (C) and (D), respectively; and

(B) by striking subparagraph (A) and inserting the following: