S. 134

*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 ''Alzheimer's Accountability and Investment Act''.

**SEC. 2. EXTENSION OF PROJECT.**

Section 2 of the National Alzheimer's Project Act (42 U.S.C. 11225) is amended—

(1) by redesignating subsection (h) as subsection (i); and

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

''(h) PROFESSIONAL JUDGMENT BUDGET.—For fiscal year 2024 and each subsequent fiscal year, the Director of the National Institutes of Health shall prepare and submit, directly to the President for review and transmittal to Congress, after reasonable opportunity for comment, but without change, by the Secretary of Health and Human Services and the Advisory Council, an annual budget estimate for the initiatives of the National Institutes of Health pursuant to the reports and recommendations made under this Act, including an estimate of the number and type of personnel needs for the National Institutes of Health.''.

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 S. 134, the Alzheimer's Accountability and Investment Act led by Senators Collins and Markey. The House companion bill, H.R. 620, is led by Representatives Smith of New Jersey and Tonko.

In the United States, health and long-term costs for individuals living with Alzheimer's disease and other dementias are projected to reach $360 billion in 2024. Around 64 percent of these costs are expected to be covered by Medicare and Medicaid with patients on the hook for the other $90 billion in out-of-pocket spending.

This tremendous cost does not even include the value of our unpaid caregivers, which was estimated to be $350 billion in 2023, amounting to over 18 billion hours of care.

In addition, individuals with dementias are more likely to have other chronic conditions, such as heart disease, diabetes, and kidney disease.

This bill would require the NIH to submit an annual budget estimate to Congress so that we may effectively assess the current resources needed to achieve the goals of the National Alzheimer's Project.

Continued investments in research to prevent and treat Alzheimer's disease and dementia will improve the quality of life for millions of Americans, with the simultaneous hope of achieving significant long-term financial savings.

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

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

Mr. Speaker, I rise to speak in support of S. 134, the Alzheimer's Accountability and Investment Act.

This bill would require the National Institutes of Health to annually submit an estimate of its budget and personnel needs for carrying out initiatives related to the National Alzheimer's Project.

The Energy and Commerce Committee reported out this bipartisan bill sponsored by Representatives CHRIS SMITH and PAUL TONKO this spring.

According to the Alzheimer's Association 2024 report, the annual cost of caring for people with Alzheimer's or other types of dementia will be about $360 billion this year alone. That is $15 billion higher than in 2023.

The report also found that 6.9 million Americans aged 65 and older have Alzheimer's dementia, with nearly 185,000 residing in my State of New Jersey. Nationwide, between 2000 and 2021, the number of deaths from Alzheimer's disease more than doubled, increasing 141 percent.

In order to make sure we meet the goals set out by the National Alzheimer's Project, which the House is also considering today, we must make sure that NIH has our support. S. 134 will require that the NIH submit a professional judgment budget for the National Alzheimer's Project so that we can identify the needs of the agency.

With this information, we can be assured that the Nation's experts are speaking directly to Congress on resources they need to effectively treat the disease and effectively communicate the capacity needs of NIH.

I encourage my colleagues to vote ''yes'' on S. 134 so that we can continue our commitment to combat Alzheimer's disease.

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

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, whatever we can do to help prevent or deal with more effectively with the Alzheimer's disorder cases, we should support it.

For that reason, I ask all my colleagues to support this bill on a bipartisan basis. 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, S. 134.

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.

## SICKLE CELL DISEASE AND OTHER HERITABLE BLOOD DISORDERS RESEARCH, SURVEILLANCE, PREVENTION, AND TREATMENT ACT OF 2023

Mr. BUCSHON. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 3884) to amend title XI of the Public Health Service Act to reauthorize the program providing for sickle cell disease and other heritable blood disorders research, surveillance, prevention, and treatment, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 3884

*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 2023''.*

***SEC. 2. REAUTHORIZATION OF SICKLE CELL DISEASE AND OTHER HERITABLE BLOOD DISORDERS RESEARCH, SURVEILLANCE, PREVENTION, AND TREATMENT.***

*Section 1106(b) of the Public Health Service Act (42 U.S.C. 300b–5(b)) is amended—*

*(1) in paragraph (3)(A), by inserting '', grant, or cooperative agreement'' after ''contract''; and*

*(2) in paragraph (6), by striking ''$4,455,000 for each of fiscal years 2019 through 2023'' and inserting ''$8,205,000 for each of fiscal years 2024 through 2028''.*

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. 3884, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act led by Congressman MICHAEL BURGESS.

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Sickle cell disease is the most common inherited blood disorder in the United States and impacts about

100,000 Americans. This disease causes red blood cells to become rigid and form into a crescent, or sickle, shape; restricts blood flow; and can lead to serious health problems throughout the body.

H.R. 3884 will continue important programs and activities administered by CDC and HRSA that are aimed to support research, prevention, and treatment for sickle cell disease and other blood disorders through fiscal year 2028.

It is critical to reauthorize this legislation so patients, families, and providers can be further educated on the condition and foster partnerships between clinicians and community organizations to help improve access to care.

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

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

Mr. Speaker, I rise to speak in support of H.R. 3884, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act.

This bill reauthorizes the sickle cell disease treatment demonstration program and data collection administered by the Centers for Disease Control and Prevention and the Health Resources Services Administration.

At our Energy and Commerce Committee hearing in June of last year, we heard directly about the importance of this reauthorization to continue critical Federal efforts to improve the lives of the approximately 100,000 Americans living with sickle cell disease. In my State of New Jersey, we have 2,000 cases of sickle cell disease, with an estimated 80 to 90 new cases each year. New Jersey is among the top 10 States with the highest prevalence of sickle cell disease.

Thanks in part to programs such as the bill before us, our Nation has seen improvements in data collection, newborn screening, and research efforts for sickle cell disease. However, there is still a lot of work to be done. Sickle cell disease patients still experience several barriers to appropriate treatment and care.

One barrier is underresourced care programs, leading many patients to rely on emergency care rather than regular, preventive treatment.

There is also still mistrust in the healthcare system among many African-American patients, socioeconomic disparities within the sickle cell disease community, and potential discrimination within our healthcare system. While considerable work remains before us, this is an important step to continue the necessary Federal investments to improve health outcomes, increase outcomes to innovative gene therapies, and lower the healthcare costs for many of the Nation's most vulnerable populations.

I thank Representative DAVIS and Dr. BURGESS for their advocacy and leadership on this legislation. We know that with early diagnosis and support for effective evidence-based interventions, we can save lives.

Mr. Speaker, I urge my colleagues to support the bipartisan reauthorization bill, and I reserve the balance of my time.

Mr. BUCSHON. Mr. Speaker, I yield 5 minutes to the gentleman from Texas (Mr. BURGESS).

Mr. BURGESS. Mr. Speaker, I thank Dr. BUCSHON from Indiana for yielding me the time on such an important reauthorization that we are undertaking today.

Mr. Speaker, 2018 was the last authorization for sickle cell research. Prior to that, it had been part of the 2004 Bush tax cuts, and it has been a long time since this Congress had turned its attention to the problems encountered by people who suffer from the diagnosis of sickle cell disease. Fortunately, in 2018, President Trump signed a bill into law, and now we are going to reauthorize that bill in this Congress.

That is a good thing.

I can remember sitting in a hearing in 2016 where the sickle cell disease advocate told us that it had been fully 40 years, four decades, since the Food and Drug Administration had approved a new therapy for sickle cell.

Fortunately, we are well past those days now, and on the horizon are a number of newer therapies. Ranking Member PALLONE mentioned cell and gene therapies. A lot of work was done when the Committee on Energy and Commerce did the CURES bill in 2016. There are now newer therapies on the horizon that were not even contemplated the last time that this bill was authorized.

Mr. Speaker, I was in practice for 30 years. I worked with families and with patients suffering from this very complex disease. Proper treatment requires knowledge, intervention, and care coordination. It is important that we have the resources to encourage more research and more data to better inform how to evaluate treatment plans while improving the quality of life for patients.

This legislation will continue to improve physician and patient education, as well as assist with best practices for care coordination. By having access to these programs, the patient and the physician will continue to have the ability to identify the problem early on, providing more time to arrest the effects of the disease from having long-term effects on the well-being of the patient.

I certainly thank my fellow Members, Representative CARTER of Georgia, and, of course, Representative DAVIS of Illinois for his longstanding work in this regard and for helping educate me as to the importance of advancing this research and advancing this reauthorization through the many steps it has taken over the last 20 years. I am grateful for the direction and the wise counsel provided by the gentleman from Illinois (Mr. DAVIS) on this important issue.

Once again, Mr. Speaker, I thank Representative BUCSHON for yielding me the time, and I thank the committee for working on this important topic.

Mr. PALLONE. Mr. Speaker, I yield such time as he may consume to the gentleman from Illinois (Mr. DAVIS), who is the Democratic sponsor of the bill.

Mr. DAVIS of Illinois. Mr. Speaker, first of all, I thank Dr. BURGESS for his tremendous advocacy on this and other legislative initiatives designed to improve the quality of health and healthcare in America.

Mr. Speaker, the consequences and complications of sickle cell disease are extreme. According to the Sickle Cell Disease Association of America, they have studied and reported that common complications with this disease include early childhood death from infection; stroke in young children and adults; lung problems similar to pneumonia; chronic damage to organs, including the kidney, leading to kidney failure, and to the lungs, causing pulmonary hypertension; and severe painful episodes. In fact, pain episodes are a hallmark of sickle cell disease.

More than 2.5 million Americans have the sickle cell trait. The sickle cell trait is found in 1 in 12 African Americans. There is a one in four chance that a child born to parents who both have the sickle cell trait will develop the sickle cell disease. The average lifespan for an adult with sickle cell disease is 45 years. The sickle cell disease affects an estimated 100,000 Americans, primarily African Americans, Hispanics, and other ethnic groups.

Mr. Speaker, I would also note that the devastation of this disease on those who are affected by it is, indeed, tremendous. I have had firsthand experience with it by virtue of having run a sickle cell community education project for the University of Illinois in Chicago and encountered many of the patients and their families. I saw the pain and suffering firsthand.

In 2004, Senator James Talent and I, along with our colleagues in Congress, introduced the Sickle Cell Disease Act, a bill designed to do more to improve the treatment and prevention of sickle cell disease. Specifically, as part of the American Jobs Creation Act, this bill was enacted.

In the 115th Congress, Senators TIM SCOTT and CORY BOOKER, Representative MICHAEL BURGESS, Representative G.K. Butterfield, and I sponsored the House companion bill to the Senate and supported a bipartisan and bicameral bill, S. 2465-enacted, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018. This reauthorized law had continued to improve the treatment and preventive measures to reduce the risk

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 heartbreaking 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.*