

H.R. 5561

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 “Early Hearing Detection and Intervention Act of 2021”.

SEC. 2. REAUTHORIZATION OF PROGRAM FOR EARLY DETECTION, DIAGNOSIS, AND TREATMENT REGARDING DEAF AND HARD-OF-HEARING NEWBORNS, INFANTS, AND YOUNG CHILDREN.

Section 399M(f) of the Public Health Service Act (42 U.S.C. 280g–1(f)) is amended—

(1) in paragraph (1), by striking “\$17,818,000 for fiscal year 2018, \$18,173,800 for fiscal year 2019, \$18,628,145 for fiscal year 2020, \$19,056,592 for fiscal year 2021, and \$19,522,758 for fiscal year 2022” and inserting “\$17,818,000 for each of fiscal years 2022 through 2026”;

(2) in paragraph (2), by striking “\$10,800,000 for fiscal year 2018, \$11,026,800 for fiscal year 2019, \$11,302,470 for fiscal year 2020, \$11,562,427 for fiscal year 2021, and \$11,851,488 for fiscal year 2022” and inserting “\$16,000,000 for each of fiscal years 2022 through 2026”; and

(3) in paragraph (3), by striking “fiscal years 2011 through 2015” and inserting “fiscal years 2022 through 2026”.

SEC. 3. GAO STUDY ON STATE EARLY HEARING DETECTION AND INTERVENTION PROGRAMS.

(a) IN GENERAL.—The Comptroller General of the United States shall conduct a study reviewing State early hearing detection and intervention (in this section referred to as “EHDI”) programs. Such study shall—

(1) analyze how information collected through such programs informs what is known about EHDI activities to ensure that newborns, infants, and young children have access to timely hearing screenings and early interventions, including information on any disparities in such access;

(2) analyze what is known about how parents use State EHDI websites to seek health and programmatic guidance related to their child’s hearing loss diagnosis; and

(3) identify efforts and any promising practices of the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the National Institute on Deafness and Other Communication Disorders, and State EHDI programs—

(A) to address disparities in outreach for, or access to, timely hearing screenings and early interventions; and

(B) to ensure that EHDI follow-up services are communicated and made available to medically underserved populations, including racial and ethnic minorities.

(b) REPORT.—Not later than two years after the date of the enactment of this Act, the Comptroller General shall—

(1) complete the study under subsection (a) and submit a report on the results of the study to—

(A) the Committee on Energy and Commerce of the House of Representatives; and

(B) the Committee on Health, Education, Labor, and Pensions of the Senate; and

(2) make such report publicly available.

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

The Chair recognizes the gentleman from New Jersey.

GENERAL LEAVE

Mr. PALLONE. 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 on H.R. 5561.

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

There was no objection.

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

Over the last 20 years, we have been very successful in addressing one of the most common birth defects affecting America’s children, congenital hearing loss. Children with this condition are born with hearing loss and are at risk for delays in speech, language, social, and emotional development. Fortunately, early detection and intervention is highly effective in preventing these adverse effects.

Since the year 2000, Congress has passed and subsequently reauthorized Early Hearing Detection and Intervention programs, also known as EHDI programs; and these programs support State and territory programs and systems of care to identify and support children who are deaf or hard of hearing. As a result of these EHDI programs, early hearing loss screening, diagnosis, and treatment services have greatly increased over the last 20 years.

Consider that before 1993, only 1 in 10 newborns were screened for hearing loss. Recent data indicates that today, 97 percent of all infants are screened within the first month of their lives; 77 percent of infants receive audiological evaluations and diagnosis by 3 months of age; and 70 percent of infants were enrolled in early intervention services before 6 months of age. These are remarkable achievements that help ensure all children with hearing loss have the same opportunities as children who can hear.

So today, we are considering a bill that will help us build on these achievements. H.R. 5561, the Early Hearing Detection and Intervention Act of 2021, would extend funding for the EHDI programs for 5 years through fiscal year 2026. This legislation will ensure that these services continue to be available for children that are deaf or hard of hearing.

I want to commend our Health Subcommittee Ranking Member GUTHRIE for his leadership on this bill. I urge all my colleagues to support it.

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

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

Mr. Speaker, I rise today in support of my bill, H.R. 5561, the Early Hearing Detection and Intervention Act, which is also co-led by my Energy and Commerce Committee colleague, Representative MATSUI.

Hearing loss in children continues to be all too prevalent in the United States. According to recent Centers for Disease Control and Prevention data, almost 15 percent of children ages six to 19 experience either low or high-frequency hearing loss in one or both ears.

The Early Hearing Detection and Intervention program, administered through CDC and the Health Resources and Services Agency, has helped providers to quickly identify babies and young children who are born deaf or hard of hearing, which has led to improved health outcomes and brought hope to so many families.

H.R. 5561 reauthorizes Federal support for these important statewide pro-

grams that promote early detection, diagnosis, and treatment of deaf and hearing impaired newborns, infants, and young children through 2026.

My bill will redouble our efforts to truly open the world of communication to children experiencing hearing loss. I urge my colleagues to support this bill.

Mr. Speaker, I have no further speakers, and I yield back the balance of my time.

Mr. PALLONE. Mr. Speaker, I urge support for this bill on a bipartisan basis, and I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from New Jersey (Mr. PALLONE) that the House suspend the rules and pass the bill, H.R. 5561, as amended.

The question was taken.

The SPEAKER pro tempore. In the opinion of the Chair, two-thirds being in the affirmative, the yeas have it.

Mr. WEBER of Texas. Mr. Speaker, on that I demand the yeas and nays.

The SPEAKER pro tempore. Pursuant to section 3(s) of House Resolution 8, the yeas and nays are ordered.

Pursuant to clause 8 of rule XX, further proceedings on this motion are postponed.

IMPROVING THE HEALTH OF CHILDREN ACT

Mr. PALLONE. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 5551) to amend title III of the Public Health Service Act to reauthorize the National Center on Birth Defects and Developmental Disabilities, and for other purposes, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 5551

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 “Improving the Health of Children Act”.

SEC. 2. REAUTHORIZATION OF THE NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES.

Section 317C of the Public Health Service Act (42 U.S.C. 247b–4) is amended—

(1) by striking subsection (a)(4) and inserting the following:

“(4) SPECIFIC PROGRAMS.—The Secretary, acting through the Director of the Center, shall continue to carry out programs related to—

“(A) early identification of developmental delay and disability;

“(B) birth defects;

“(C) folic acid;

“(D) cerebral palsy;

“(E) intellectual disabilities;

“(F) child development;

“(G) newborn screening;

“(H) autism;

“(I) fragile X syndrome;

“(J) fetal alcohol spectrum disorders and other conditions related to prenatal substance use;

“(K) pediatric genetic disorders;

“(L) neuromuscular diseases;

“(M) congenital heart defects;

“(N) attention-deficit/hyperactivity disorder;

“(O) stillbirth;

“(P) Tourette Syndrome; or

“(Q) any other relevant disease, disability, disorder, or condition, as determined the Secretary.”;

(2) in subsection (c), in the matter preceding paragraph (1), by striking “Not later than February 1” and all that follows through “2 fiscal years—” and inserting the following: “The Secretary shall submit biennially to the Committee

on Energy and Commerce of the House of Representatives, and the Committee on Health, Education, Labor, and Pensions of the Senate, a report that—"; and

(3) in subsection (f), by striking "such sums as may be necessary for each of fiscal years 2003 through 2007" and inserting "\$186,010,000 for each of fiscal years 2022 through 2026".

SEC. 3. EFFECTS OF FOLIC ACID IN PREVENTION OF BIRTH DEFECTS.

Section 317J of the Public Health Service Act (42 U.S.C. 247b-11) is amended by striking subsection (e) (relating to authorization of appropriations).

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

The Chair recognizes the gentleman from New Jersey.

GENERAL LEAVE

Mr. PALLONE. 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 on H.R. 5551.

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

There was no objection.

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

I rise in support of H.R. 5551, the Improving the Health of Children Act, which reauthorizes the National Center on Birth Defects and Developmental Disabilities. This center was established by Congress in 2000 to improve the health of millions of our Nation's most vulnerable citizens, our infants and children, people with disabilities, and people with blood disorders. It is the only center at the Centers for Disease Control and Prevention whose mission focuses on these populations.

Birth defects, Mr. Speaker, affect 1 in 33 babies and are a leading cause of infant death in the United States. Children with birth defects who survive often experience lifelong physical and mental disabilities. In addition, over 500,000 children are diagnosed with a developmental disability each year.

Blood disorders such as sickle cell disease, anemia, and hemophilia, affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status.

So H.R. 5551, sponsored by Representatives CARTER and TRAHAN, reauthorizes the work of this center for 5 years and helps maintain the programmatic focus of the center.

It has been 15 years since the last authorization, and the importance of the center's work continues to grow. Whether it be supporting partnerships to continue research on autism or coordinating a rapid response to Zika, the center plays a critical role in preventing birth defects and helping people with disabilities and blood disorders live healthy and productive lives.

So, Mr. Speaker, I urge my colleagues to support this bill so that we can ensure vital surveillance and re-

search continue to focus on the well-being of people with birth defects, disabilities, and blood disorders.

I reserve the balance of my time.

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

Mr. Speaker, I rise today in support of H.R. 5551, the Improving the Health of Children Act, led by my Energy and Commerce Committee colleagues, Representatives CARTER and TRAHAN.

Birth defects, unfortunately, are very common in the United States. According to recent Centers for Disease Control and Prevention data, 1 in every 33 babies are born with a birth defect each year, and birth defects are the leading cause of death for all babies.

H.R. 5551 reauthorizes through 2026 the National Center on Birth Defects and Developmental Disabilities, which has been critical to improving the lives of children with birth defects and their families.

This would reestablish critical programming related to birth defects, intellectual disabilities, and child development in order to bolster the center's research efforts and improve more lives.

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

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Mr. PALLONE. Mr. Speaker, I yield 3 minutes to the gentlewoman from Massachusetts (Mrs. TRAHAN), a member of the Energy and Commerce Committee and the Democratic sponsor of this bill.

Mrs. TRAHAN. Mr. Speaker, I rise in strong support of H.R. 5551, the Improving the Lives of Children Act. I sponsored this bipartisan legislation alongside Representatives BUDDY CARTER, G. K. BUTTERFIELD, and HENRY CUELLAR, because the work being done at the CDC's National Center on Birth Defects and Developmental Disabilities is tremendously important to many millions of families across our Nation.

Approximately 1 in 6 children in the United States are affected by some form of developmental disability. They include a diverse range of conditions, including ADHD, autism spectrum disorder, fragile X syndrome, and Tourette syndrome, just to name a few.

Some of these conditions have the ability to seriously impact children's lives by limiting motor ability, cognitive development, verbal communication, and behavioral development, and they often last throughout a person's lifetime.

For some developmental disabilities, we know the causes and the risk factors, but for so many others, we don't. That is why the research and advancements at the National Center on Birth Defects and Developmental Disabilities continue to be so crucial.

Since its creation in 2000, the center's dedicated staff have created a roadmap to a world where babies are born healthy, children are empowered to reach their full potential, and families are able to thrive. But there is still so much work to be done.

That is why my legislation reauthorizes the center for the first time in 15 years and provides it with the funding and resources necessary to support more than a dozen essential programs.

This bipartisan bill is key to identifying developmental disabilities early and bolstering doctors' capacity to intervene, both of which experts agree are critical in improving children's ability to learn new skills and reducing the financial burden on families.

Mr. Speaker, when children and adults with disabilities receive the care and services they need, their quality of life improves dramatically.

The goal of the National Center on Birth Defects and Developmental Disabilities is to ensure that every person with a disability has access to the support they need from a young age, and our legislation helps achieve it.

That is why it is supported by so many individuals and families across America who want nothing more than for Congress to advance policies that give people living with disabilities the dignity, respect, and opportunities they need to succeed.

I look forward to casting my vote in favor of this legislation, and I encourage all of my colleagues to join me in doing the same.

Mr. GUTHRIE. Mr. Speaker, I yield 2 minutes to the gentleman from Georgia (Mr. CARTER).

Mr. CARTER of Georgia. Mr. Speaker, I thank the chairman and ranking member for bringing this important legislation to the floor. The Improving the Health for Children Act is up for vote today. It is an extremely important bill.

As we all know, the National Center on Birth Defects and Developmental Disabilities does phenomenal work to protect, prevent, and research birth defects and intellectual disabilities for a wide range of conditions.

They also provide much needed educational resources to parents and caregivers about the conditions a child may have, and they work to raise awareness about conditions that may be hard to identify.

Unfortunately, the center has been operating under an expired authorization since 2007. We must not forgo our commitment to these children.

This legislation reaffirms congressional support of the center, expands their scope to study more conditions, and provides an increase, per authorization, so that they can continue to carry out the great work they do.

I want to thank the bipartisan supporters of this legislation for the help in authoring this bill, Representatives TRAHAN, CUELLAR, BUTTERFIELD, and HUDSON, and I urge a "yes" vote on passage of this important legislation today.

Mr. GUTHRIE. Mr. Speaker, I encourage my colleagues to vote for this bill, and I yield back the balance of my time.

Mr. PALLONE. Mr. Speaker, I urge support on a bipartisan basis, and I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from New Jersey (Mr. PALLONE) that the House suspend the rules and pass the bill, H.R. 5551, 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. WEBER of Texas. Mr. Speaker, on that I demand the yeas and nays.

The SPEAKER pro tempore. Pursuant to section 3(s) of House Resolution 8, the yeas and nays are ordered.

Pursuant to clause 8 of rule XX, further proceedings on this motion are postponed.

CARDIOVASCULAR ADVANCES IN RESEARCH AND OPPORTUNITIES LEGACY ACT

Mr. PALLONE. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 1193) to amend title IV of the Public Health Service Act to direct the Director of the National Institutes of Health, in consultation with the Director of the National Heart, Lung, and Blood Institute, shall establish a program under which the Director of the National Institutes of Health shall support or conduct research on valvular 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. 1193

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 “Cardiovascular Advances in Research and Opportunities Legacy Act”.

SEC. 2. GRANTS FOR VALVULAR HEART DISEASE RESEARCH.

Subpart 2 of part C of title IV of the Public Health Service Act (42 U.S.C. 285b et seq.) is amended by inserting after section 424C (42 U.S.C. 285b-7c) the following:

“SEC. 424D. GRANTS FOR VALVULAR HEART DISEASE RESEARCH.

“(a) IN GENERAL.—The Director of the National Institutes of Health, in consultation with the Director of the Institute, shall support or conduct research regarding valvular heart disease.

“(b) SUPPORT GUIDELINES.—The distribution of funding authorized under subsection (a) may be used to pursue the following outcomes:

“(1) Using precision medicine and advanced technological imaging to generate data on individuals with valvular heart disease.

“(2) Identifying and developing a cohort of individuals with valvular heart disease and available data.

“(3) Corroborating data generated through clinical trials to develop a prediction model to distinguish individuals at high risk for sudden cardiac arrest or sudden cardiac death from valvular heart disease.

“(4) For other outcomes needed to acquire necessary data on valvular heart disease.

“(c) MITRAL VALVE PROLAPSE WORKSHOP.—Not later than one year after the date of the enactment of this section, the Director of the Institute shall convene a workshop composed of subject matter experts and stakeholders to identify research needs and opportunities to develop prescriptive guidelines for treatment of individuals with mitral valve prolapse.

“(d) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there is authorized to be appropriated \$20,000,000 for each of fiscal years 2022 through 2026.”.

SEC. 3. PROGRAMS OF CENTERS FOR DISEASE CONTROL AND PREVENTION.

Part B of title III of the Public Health Service Act (42 U.S.C. 243 et seq.) is amended by inserting after section 312 the following section:

“SEC. 312A. PREVENTION OF SUDDEN CARDIAC DEATH AS A RESULT OF VALVULAR HEART DISEASE.

“(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, may carry out projects to increase education, awareness, or diagnosis of valvular heart disease and to reduce the incidence of sudden cardiac death caused by valvular heart disease. Such projects may be carried out by the Secretary directly or through awards of grants or contracts to public or non-profit private entities. The Secretary may directly (or through such awards) provide technical assistance with respect to the planning, development, and operation of such projects.

“(b) CERTAIN ACTIVITIES.—Upon availability of applicable data, projects carried out under subsection (a) may include—

“(1) continuing the activities at the Division for Heart Disease and Stroke Prevention, including those related to valvular heart disease;

“(2) broadening the awareness of the public concerning the risk factors for, the symptoms of, and the public health consequences of valvular heart disease; and

“(3) enhancing surveillance of out-of-hospital cardiac arrests to improve patient outcomes.

“(c) GRANT PRIORITIZATION.—The Secretary may, in awarding grants or entering into contracts pursuant to subsection (a), give priority to entities seeking to carry out projects that target populations most impacted by valvular heart disease.

“(d) COORDINATION OF ACTIVITIES.—The Secretary shall ensure that activities under this section are coordinated, as appropriate, with other agencies of the Public Health Service that carry out activities regarding valvular heart disease.

“(e) BEST PRACTICES.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall—

“(1) collect and analyze the findings of research conducted with respect to valvular heart disease; and

“(2) taking into account such findings, publish on the website of the Centers for Disease Control and Prevention best practices for physicians and other health care providers who provide care to individuals with valvular heart disease.”.

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

The Chair recognizes the gentleman from New Jersey.

GENERAL LEAVE

Mr. PALLONE. 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 on H.R. 1193.

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

There was no objection.

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

Mr. Speaker, valvular heart disease is a rising health threat to many otherwise healthy people. Each year, more than 25,000 Americans lose their lives

to valvular heart disease, and they are predominantly young women. Unfortunately, the disease's reach is only increasing with more than 5 million diagnoses each year.

Despite this rising incidence, there is so much that we do not know about valvular heart disease. Specifically, we do not have a good understanding about what makes the disease life-threatening.

Today, we are taking an important step to address this gap by considering H.R. 1193, the CAROL Act. I commend Representative BARR for introducing this legacy bill in honor of his late wife, Carol, who died unexpectedly in June of 2020 from an underlying valvular heart disease condition. This bill will help other families avoid the same tragedy his family has faced.

The CAROL Act will expand research on valvular heart disease and its treatment by authorizing a grant program administered by the National Institutes of Health in collaboration with the National Heart, Lung, and Blood Institute. It will also require the Centers for Disease Control and Prevention to carry out projects to increase education, awareness, and diagnosis of valvular heart disease and to reduce cardiac deaths caused by valvular heart disease.

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

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

Mr. Speaker, I rise today in strong support of H.R. 1193, the Cardiovascular Advances and Opportunities Legacy Act, or the CAROL Act, introduced by my good friend and fellow Kentuckian, Representative ANDY BARR.

Mr. Speaker, Congress is like a family, and we certainly laugh together and we certainly argue with each other, but there are times we cry with each other. I will never forget the phone call that I received from ROBERT ADERHOLT telling me that Carol Barr, who was a wonderful woman, wonderful wife, and wonderful mother, had passed away.

Our friend and colleague, Representative ANDY BARR, has introduced this bill to honor his wife, who passed away from mitral valve prolapse.

Heart disease continues to be the leading cause of death for most demographic groups in the United States. Over 600,000 Americans die from heart disease each year. This is equal to one person every 36 seconds.

We know that taking early action is critical to surviving a heart condition. People need to know the warning signs and symptoms. Understanding the gaps in education and information sharing will help the healthcare system better detect these warning signs.

This bill authorizes grants administered by the National Heart, Lung, and Blood Institute to support research on valvular heart disease and convenes subject matter experts to identify research opportunities to develop more