



COMMITTEE ON
ENERGY & COMMERCE

CHAIRMAN FRANK PALLONE, JR.

MEMORANDUM

October 18, 2021

To: Subcommittee on Health Members and Staff

Fr: Committee on Energy and Commerce Staff

Re: Legislative Hearing on “Enhancing Public Health: Legislation to Protect Children and Families”

On Wednesday October 20, 2021, at 10:30 a.m. (EDT), in the John D. Dingell Room, 2123 of the Rayburn House Office Building, and via Cisco WebEx online video conferencing, the Subcommittee on Health will hold a legislative hearing entitled, “Enhancing Public Health: Legislation to Protect Children and Families.”

I. H.R. 623, THE “GABRIELLA MILLER KIDS FIRST RESEARCH ACT 2.0”

A. Background

Cancer is the leading cause of death in American children, however, only four percent of the National Cancer Institute’s (NCI) budget is dedicated to pediatric cancer research.^{1,2} The Gabriella Miller Kids First Pediatric Research Program (Kids First) was established under the Common Fund at the National Institutes of Health (NIH) in 2014 after passage of the original Gabriella Miller Kids First Research Act.³ The goal of the Kids First program is to enhance collaborative research on childhood cancer and structural birth defects, including the development of a large-scale database of clinical and genetic data to discover shared genetic pathways between the disorders.⁴ The law is named in honor of Gabriella Miller, a resident of Virginia who was diagnosed with an inoperable brain tumor and passed away in 2013 at the age of ten years old.

¹ National Cancer Institute, *Cancer in Children and Adolescents* (accessed Oct. 12, 2021) (www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet).

² National Cancer Institute, *NCI Childhood Cancers Research Investment* (accessed Oct. 12, 2021) (4sqclobberscancer.files.wordpress.com/2020/04/ncifunding2008_2017_edited-1-1.pdf).

³ Gabriella Miller Kids First Research Act, Pub. L. No. 113-94.

⁴ National Institutes of Health, *Common Fund Programs: Gabriella Miller Kids First* (Accessed October 12, 2021) (commonfund.nih.gov/kidsfirst).

B. Legislation

H.R. 623, the “Gabriella Miller Kids First Research Act 2.0,” introduced by Rep. Wexton (D-VA) and 17 other original cosponsors, authorizes an additional source of funding for the Kids First program by redirecting penalties levied against pharmaceutical, cosmetic, supplement, and medical device companies by the U.S. Securities and Exchange Commission (SEC) for violating the Foreign Corrupt Practices Act towards the program. The bill also ensures that the Kids First program should prioritize pediatric research that does not duplicate existing research activities at NIH.

II. H.R. 1193, THE “CARDIOVASCULAR ADVANCES IN RESEARCH AND OPPORTUNITIES LEGACY ACT” OR THE “CAROL ACT”

A. Background

Valvular heart disease (VHD) is caused by damage or disease affecting the valves of the heart that regulate blood flow into the heart.⁵ VHD affects 2.5 percent of the general U.S. population and 13 percent of the elderly population.⁶ It is the cause of around 27,000 deaths in the United States each year and is on the rise, accounting for than five million diagnoses each year.^{7,8} Despite the rising incidence of VHD, there has been little research on the condition and its treatment.

B. Legislation

H.R. 1193, the “CAROL Act,” introduced by Rep. Andy Barr (R-KY), seeks to expand research on valvular heart disease and its treatment. This legislation authorizes a grant program administered by NIH in collaboration with the National Heart, Lung, and Blood Institute (NHLBI) to support research on valvular heart disease and for convening a workshop of subject matter experts and stakeholders to identify research needs and treatment guidelines for individuals diagnosed with mitral valve prolapse, a type of VHD. The bill also requires the Centers for Disease Control and Prevention (CDC) to carry out projects to increase education, awareness, or diagnosis of valvular heart, and to reduce cardiac deaths caused by valvular heart disease. This bill is named in honor of Carol Leavell Barr, wife of Rep. Barr, who died in 2020,

⁵ Centers for Disease Control and Prevention, Valvular Heart Disease (accessed October 12, 2021) (www.cdc.gov/heartdisease/valvular_disease.htm).

⁶ *Id.*

⁷ *Id.*

⁸ American College of Cardiology, *Succeed in Managing Heart Valve Disease Initiative* (accessed Oct. 12, 2021) (www.acc.org/Tools-and-Practice-Support/Quality-Programs/http%3a%2f%2fwww.acc.org%2fTools-and-Practice-Support%2fQuality-Programs%2fValvular-Heart-Disease-Initiatives).

of sudden cardiac arrest most likely brought on by a ventricular arrhythmia, a complication of VHD.

III. H.R. 1956, THE “INCREASING ACCESS TO QUALITY CARDIAC REHABILITATION CARE ACT OF 2021”

A. Background

Heart disease is the leading cause of death for both men and women in the United States, resulting in approximately 659,000 deaths every year.⁹ About 805,000 Americans experience a heart attack each year, and approximately 200,000 of these heart attacks are recurrent events.¹⁰ Cardiac and pulmonary rehabilitation programs for heart attack survivors and others with heart disease can help to reduce these recurrences and improve health outcomes. These programs often include supervised exercise, education, and counselling among other services.¹¹ Cardiac and pulmonary rehabilitation programs have many benefits for heart disease patients, including reduced risk of hospital readmission and improved quality of life.¹² Despite these benefits, it is estimated that only one in four Medicare beneficiaries eligible for cardiac and pulmonary rehabilitation services receives them.¹³

Under current law, only physicians are authorized to order and supervise cardiac and pulmonary rehabilitation care in the Medicare program. The Bipartisan Budget Act of 2018 authorized physician assistants, nurse practitioners, and clinical nurse specialists to provide direct supervision for cardiac and pulmonary rehabilitation care beginning in 2024.¹⁴

B. Legislation

H.R. 1956, the “Increasing Access to Quality Cardiac Rehabilitation Care Act of 2021,” introduced by Reps. Blunt-Rochester (D-DE), Smith (R-NE), Kilmer (D-WA), Fitzpatrick (R-PA), and Welch (D-VT), aims to expand patient access to cardiac and pulmonary rehabilitation care. The legislation would authorize physician assistants, nurse practitioners, and clinical nurse specialists to supervise cardiac and pulmonary rehabilitation care under Medicare beginning in

⁹ Centers for Disease Control and Prevention, *Heart Disease in the United States* (Sept. 27, 2021) (www.cdc.gov/heartdisease/facts.htm).

¹⁰ *Id.*

¹¹ American Heart Association, *What is Cardiac Rehabilitation* (July 31, 2016) (www.heart.org/en/health-topics/cardiac-rehab/what-is-cardiac-rehabilitation).

¹² Johns Hopkins Medicine, *Cardiac Rehabilitation: Big Benefits with Perseverance* (2021) (www.hopkinsmedicine.org/health/wellness-and-prevention/cardiac-rehabilitation-big-benefits-with-perseverance).

¹³ American Heart Association, *Only One in Four Medicare Patients Participate in Cardiac Rehabilitation* (January 14, 2021) (newsroom.heart.org/news/only-one-in-four-medicare-patients-participate-in-cardiac-rehabilitation).

¹⁴ Bipartisan Budget Act of 2018, Pub. L. No. 115-123.

2022, two years earlier than under current law. It would also authorize such providers to order cardiac and pulmonary rehabilitation care.

IV. H.R. 2161, THE “CHILDREN AND MEDIA RESEARCH ADVANCEMENT ACT” OR THE “CAMRA ACT”

A. Background

It has been estimated that screen time for children increased as much as 50 percent during the coronavirus disease of 2019 (COVID-19) pandemic.¹⁵ Recent surveys also suggest that young people are increasingly turning to social media when seeking to manage mental health; one in five teens and young adults consider social media as “very” important to them for getting support and young people with moderate to severe depressive symptoms are almost twice as likely to use social media “almost constantly”.¹⁶ Exposure to hate speech on social media, including body-shaming, racism, sexism, and homophobia has also increased substantially since 2020.¹⁷

B. Legislation

H.R. 2161, the “CAMRA Act,” introduced by Reps. Raskin (D-MD), Gonzales (R-OH), and Trahan (D-MA), authorizes the NIH to lead a research program on the effects of technology and media on infants, children, and adolescents in core areas of cognitive, physical, and socio-emotional development. This research would investigate the effects on children of exposure to, and use of, media such as mobile devices, computers, social media, software applications, websites, television, motion pictures, artificial intelligence, video games, and virtual and augmented reality.

V. H.R. 3749, THE “KATHERINE’S LAW FOR LUNG CANCER EARLY DETECTION AND SURVIVAL ACT OF 2021”

A. Background

Nearly 25 percent of all cancer deaths in the United States are due to lung cancer.¹⁸ Generally, lung cancer screening is only covered by insurance for those who are over the age of 50, do not show symptoms of lung cancer, are current smokers or quit within the last 15 years,

¹⁵ *Kids’ screen time up 50% during the pandemic*, Axios (Jan. 17, 2021) (www.axios.com/kids-screen-time-pandemic-112650a6-743c-4c15-b84a-7d86103262bb.html).

¹⁶ Common Sense Media, *Coping with COVID-19: How Young People Use Digital Media to Manage their Mental Health* (accessed Oct. 12, 2021) (www.common Sense Media.org/sites/default/files/uploads/research/2021-coping-with-covid19-full-report.pdf).

¹⁷ *Id.*

¹⁸ American Cancer Society Journals, *Cancer Statistics, 2021* (Jan. 12, 2021) (acsjournals.onlinelibrary.wiley.com/doi/full/10.3322/caac.21654).

and have a smoking history of 30 “pack years.”¹⁹ Although the majority of lung cancer deaths can be directly attributed to smoking, many non-smokers develop lung cancer.²⁰

B. Legislation

H.R. 3749, the “Katherine’s Law for Lung Cancer Early Detection and Survival Act of 2021,” introduced by Reps. Boyle (D-PA), DeSaulnier (D-CA), and Lowenthal (D-CA), seeks to expand coverage of lung cancer screenings in individuals ages 40-49, with no previous history of smoking or who otherwise have a high-risk of developing lung cancer due to genetic, occupations, family history, or other exposures by adding it to the list of preventive health services required to be covered by group and individual health insurance plans under the Public Health Service Act with no cost-sharing. This bill is named in honor Katherine Bensen, the daughter of former Rep. Rick Nolan (D-MN). Katherine died in 2020 after a five-year battle with lung cancer at the age of 46; Katherine did not have a history of smoking.²¹

VI. H.R. 4555, THE “ORAL HEALTH LITERACY AND AWARENESS ACT OF 2021”

A. Background

Oral health, defined as the health of the teeth, gums, and the entire oral-facial system, is an integral component of general health and well-being. Cavities (tooth decay), gum (periodontal) disease, and oral cancer are the most common yet preventable diseases affecting oral health.²² More than one in four adults have untreated cavities, and nearly half of those aged 30 or older show signs of gum disease, which if left untreated can lead to tooth loss.²³ The distal consequences of poor oral health include an annual average of 34 million school hours lost due to unplanned (emergency) dental care and an over \$45 billion loss in US productivity due to untreated dental disease.²⁴ A key tool in preventing poor oral health is the promotion of oral

¹⁹ American Lung Association, *Is lung cancer screening covered under your insurance?* (accessed October 12, 2021) (www.lung.org/getmedia/36bf8cc4-4878-4289-969e-ee6b8b112e2a/lung-cancer-insurance-chart.pdf).

²⁰ See note 18.

²¹ *Former Rep. Nolan's daughter succumbs to cancer at age 46*, Duluth News Tribune (September 15, 2020) (www.duluthnewstribune.com/news/government-and-politics/6662173-Former-Rep.-Nolans-daughter-succumbs-to-cancer-at-age-46#:~:text=Katherine%20Bensen%2C%20daughter%20of%20former,cell%20lung%20cancer%20in%202015).

²² Centers for Disease Control and Prevention, *Oral Health Conditions* (Nov. 3, 2020) (www.cdc.gov/oralhealth/conditions/index.html).

²³ Centers for Disease Control and Prevention, *Cost-Effectiveness of Oral Diseases Interventions: Power of Prevention* (May 13, 2021) (www.cdc.gov/chronicdisease/programs-impact/pop/oral-disease.htm).

²⁴ *Id.*

health literacy (OHL), or “the individual capacity to understand and use dental information to transform oral health behaviors.”²⁵ Individuals with limited OHL have been found to have increased risk for poor oral health such as higher risk for periodontal disease.²⁶ Emerging evidence suggests that improving OHL may help to increase adherence to medical instructions, self-management skills, and overall treatment outcomes.²⁷

B. Legislation

H.R. 4555, the “Oral Health Literacy and Awareness Act of 2021,” introduced by Reps. Cárdenas (D-CA) and Bilirakis (R-FL), authorizes a public education campaign across all relevant programs of the Health Resources and Services Administration (HRSA) to increase oral health literacy and awareness for fiscal years 2022 through 2026.

VII. H.R. 4612, THE “PROTECTING ACCESS TO LIFESAVING SCREENINGS ACT OF 2021” OR THE “PALS ACT OF 2021”

A. Background

The U.S. Preventative Services Task Force (USPSTF) is an independent panel of medical experts that provides evidence-based recommendations on clinical preventative services.²⁸ Health item and service recommendations rated “A” or “B” by USPSTF are covered without cost sharing by public and private health insurers.²⁹ Currently, USPSTF guidelines provide a grade “B” recommendation for biennial breast cancer screenings for women ages 50-74.³⁰ Since 2009, women ages 40-49 have not been recommended for routine screening, and instead, USPSTF has provided a grade “C” recommendation for this age group, advising that the decision to screen for breast cancer before age 50 “should be “an individual one” dependent on particular circumstances of the patient.³¹ As a result, this age group may not have coverage in public and private health insurance plans. In 2015, Congress passed a three-year moratorium on the USPSTF recommendation to allow for continued insurance coverage without cost sharing of breast cancer screenings for women ages 40-49, among other services; the moratorium was subsequently extended until January 1, 2022.³²

²⁵ Yue Sun et al., *Trends and Developments in Oral Health Literacy: A Scientometric Research Study (1991–2020)* (Mar. 1, 2021) (doi.org/10.1038/s41405-021-00066-5).

²⁶ *Id.*

²⁷ *Id.*

²⁸ U.S. Preventative Services Task Force, *About the USPSTF* (accessed Oct.11, 2021) (www.uspreventiveservicestaskforce.org/uspstf/about-uspstf).

²⁹ 42 U.S.C. 300gg-13.

³⁰ U.S. Preventative Services Task Force, *Breast Cancer: Screening* (Jan. 11, 2016) (www.uspreventiveservicestaskforce.org/uspstf/recommendation/breast-cancer-screening).

³¹ *Id.*

³² Further Consolidated Appropriations Act, 2020, Pub. L. No. 116-94.

B. Legislation

H.R. 4612, the “PALS Act of 2021,” introduced by Reps. Wasserman Schultz (D-FL) and Upton (R-MI), extends the moratorium on the implementation of the change in USPSTF breast cancer screening recommendations that was made in 2009 through January 1, 2028. The bill would also amend Medicare’s definition of screening mammography to include any digital modality (such as screening breast tomosynthesis).

VIII. H.R. 5487, THE “STILLBIRTH HEALTH IMPROVEMENT AND EDUCATION FOR AUTUMN ACT OF 2021” OR THE “SHINE FOR AUTUMN ACT OF 2021”

A. Background

Stillbirth affects one in 160 births – approximately 24,000 babies are stillborn in the United States each year.³³ Medical advances including improved prenatal care have reduced the number of late and term stillbirths, but the rate of early stillbirth has remained relatively unchanged.³⁴ Despite these numerical reductions in stillbirths, the causes of stillbirth have not been explored extensively through research.

B. Legislation

H.R. 5487, the “SHINE for Autumn Act of 2021,” introduced by Reps. Herrera Beutler (R-WA), Roybal-Allard (D-CA), Castor (D-FL), and Mullin (R-OK), seeks to improve research and data collection on stillbirths. The bill would provide grants to states for surveillance and data collection relating to stillbirth and stillbirth risk factors, develop guidelines and education materials for states departments of health, and establish the Perinatal Pathology Fellowship Program at NIH to increase research on stillbirth. The bill is named in honor of Autumn Joy, who was stillborn on July 8, 2011.³⁵

IX. H.R. 5551, THE “IMPROVING THE HEALTH OF CHILDREN ACT”

A. Background

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) was established in April 2001 as a result of “The Children’s Health Act of 2000”.³⁶ From its inception, the NCBDDD included the established programs in birth defects, genetic disorders,

³³ Centers for Disease Control and Prevention, Stillbirth (Nov. 16, 2020) (www.cdc.gov/ncbddd/stillbirth/facts.html).

³⁴ *Id.*

³⁵ *Jamie Herrera Beutler Introduces Bill to Improve U.S. Stillbirth Rate*, Office of Jamie Herrera Beutler (Oct. 5, 2021) (jhb.house.gov/news/documentsingle.aspx?DocumentID=402285) (press release).

³⁶ Children’s Health Act of 2000, Pub. L. No. 106-310.

developmental disabilities and health, including the training of public health professionals in these respective fields. The CDC estimates that one in 33 children are born with a birth defect and one in four Americans have some form of disability.^{37, 38} NCBDDD has four focus areas: (1) saving infants through surveillance, research, and prevention of birth defects and disorders; (2) helping children by understanding developmental disabilities; (3) protecting people living with blood disorders; and (4) improving the health of people living with disabilities.³⁹

B. Legislation

H.R. 5551, the “Improving the Health of Children Act,” introduced by Reps. Carter (R-GA), Cuellar (D-TX), Hudson, (R-NC), Butterfield (D-NC), and Trahan, reauthorizes NCBDDD at CDC for five years until 2026.

X. H.R. 5552, THE “LEAD POISONING PREVENTION ACT”

A. Background

Childhood lead poisoning is a serious public health concern. It is estimated that about 3.6 million American families with a child under six years old live in a home with a potential lead exposure hazard.⁴⁰ Accordingly, 500,000 U.S. children (2.5 percent) have blood lead levels that are above the average CDC reference level and are thereby, potentially dangerous.⁴¹ At high levels, lead exposure can cause comas, convulsions and even death; however, even at lower levels, lead exposure can affect children’s brain development, leading to lower intelligence quotients (IQ), impaired behavioral development (e.g. reduced attention span and increase antisocial behavior), and reduced educational attainment.⁴² There is currently no method of

³⁷ Centers for Disease Control and Prevention, *National Center on Birth Defects and Developmental Disabilities (NCBDDD)* (accessed October 12, 2021) (www.cdc.gov/ncbddd/aboutus/what-we-do.html).

³⁸ *Id.*

³⁹ *Id.*

⁴⁰ President’s Task Force on Environmental Health Risks and Safety Risks to Children, *Key Federal Programs to Reduce Childhood Lead Exposures and Eliminate Associated Health Impacts* (Nov. 2016) (ptfkeh.niehs.nih.gov/features/assets/files/key_federal_programs_to_reduce_childhood_lead_exposures_and_eliminate_associated_health_impactspresidents_508.pdf).

⁴¹ Marissa Hauptman, Rebecca Bruccoleri, and Alan D. Woolf, *An Update on Childhood Lead Poisoning Clinical Pediatric Emergency Medicine* (Sept. 2017) (doi.org/10.1016/j.cpem.2017.07.010).

⁴² World Health Organization, *Lead Poisoning* (accessed Oct. 12, 2021) (www.who.int/news-room/fact-sheets/detail/lead-poisoning-and-health).

reversing the adverse effects of lead poisoning, making preventative efforts critical to positive health outcomes.⁴³

B. Legislation

H.R. 5552, the “Lead Poisoning Prevention Act,” introduced by Reps. Walberg (R-MI) and Tonko (D-NY), establishes the Advisory Committee on Childhood Lead Poisoning Prevention to (1) coordinate efforts across federal agencies to prevent childhood poisoning; (2) review and report on childhood lead poisoning prevention practices; (3) offer recommendations to federal agencies on the improvement of national childhood lead poisoning prevention efforts; and (4) develop recommendations to state, local, Tribal, and territorial health departments for the prevention and control of childhood lead poisoning. In addition, the legislation reauthorizes the screenings, referrals, and education regarding lead poisoning program and the lead poisoning related activities grant program at the CDC.

XI. H.R. 5558, THE “PROSTATE CANCER PREVENTION ACT OF 2021”

A. Background

Prostate cancer is the second most-diagnosed cancer and the second highest cancer-related cause of death among American males.⁴⁴ Out of every 100 American men, about 13 will get prostate cancer during their lifetime and two to three will die of prostate cancer.⁴⁵ Some men are at an increased risk for prostate cancer, including Black men and those who have a family history of prostate cancer.⁴⁶ While there are currently no proven prevention strategies for prostate cancer, screening programs to detect prostate cancer early are important.⁴⁷ The survival rate for prostate cancer diagnosed in early stage is nearly 100 percent but prostate cancer diagnosed in late stage has only a 30-percent survival rate.⁴⁸

B. Legislation

⁴³ Laura Mayans, *Lead Poisoning in Children*, American Family Physician, (July 1, 2019) (www.aafp.org/afp/2019/0701/p24.html).

⁴⁴ American Cancer Society, *Key Statistics for Prostate Cancer* (Jan.12, 2021) (www.cancer.org/cancer/prostate-cancer/about/key-statistics.html).

⁴⁵ Centers for Disease Control and Prevention, *Who is At Risk for Prostate Cancer?* (Aug. 23, 2021) (www.cdc.gov/cancer/prostate/basic_info/risk_factors.htm).

⁴⁶ *Id.*

⁴⁷ Mayo Clinic, *Prostate cancer prevention: Ways to reduce your risk* (accessed Oct. 12, 2021) (www.mayoclinic.org/diseases-conditions/prostate-cancer/in-depth/prostate-cancer-prevention/art-20045641).

⁴⁸ American Cancer Society, *Survival Rates for Prostate Cancer* (Feb. 2, 2021) (www.cancer.org/cancer/prostate-cancer/detection-diagnosis-staging/survival-rates.html).

H.R. 5558, the “Prostate Cancer Prevention Act of 2021,” introduced by Reps. Dunn (R-FL) and Rush (D-IL), reauthorizes preventive health programs with respect to prostate cancer at the CDC and other agencies at the Department of Health and Human Services (HHS).

XII. H.R. 5561, EARLY HEARING DETECTION AND INTERVENTION REAUTHORIZATION ACT OF 2021

A. Background

Prior to 2000, only one in ten newborns were screened for hearing loss.⁴⁹ In 2000, Congress passed and has subsequently reauthorized federal Early Hearing Detection and Intervention (EHDI) programs at HRSA, CDC, and NIH.⁵⁰ EHDI programs support the development of services which ensure that children who are deaf and hard of hearing are identified at an early age through appropriate newborn, infant, and early childhood screening and receive optimal intervention care to enhance language, literacy, cognitive, social, and emotional development.⁵¹ Rates of EHDI services have significantly increased in the last 20 years. In 2020, CDC data reported that 97 percent of all infants were screened before reaching the age of one month, and for infants identified to be deaf or hard of hearing, 70 percent were enrolled in early intervention services before six months of age.⁵²

B. Legislation

H.R. 5561, the “Early Hearing Detection and Intervention Reauthorization Act of 2021,” introduced by Reps. Guthrie (R-KY) and Matsui (D-CA), extends the authorization for EHDI programs at HRSA, CDC, and NIH for five years until 2026.

XIII. WITNESSES

The following witnesses have been invited to testify:

Bruce L. Cassis, D.D.S., M.A.G.D.
President
Academy of General Dentistry

⁴⁹ Health Resources and Services Administration, Early Hearing Detection and Intervention (accessed October 12, 2021) (mchb.hrsa.gov/maternal-child-health-initiatives/early-hearing-detection-and-intervention.html).

⁵⁰ Hearing Loss Association of America, Early Hearing and Intervention Act (EHDI) (accessed October 12, 2021) (www.hearingloss.org/programs-events/advocacy/know-your-rights/early-hearing-detection-intervention-act-ehdi/).

⁵¹ See note 17.

⁵² *Id.*

Raymond DuBois, M.D., Ph.D.

Former President
American Association for Cancer Research

Donald M. Lloyd-Jones, M.D., Sc.M.

President
American Heart Association

Ellyn Miller

President and Founder
Smashing Walnuts Foundation

Rick Nolan

Former U.S. Representative (MN)

Jenny Radesky, M.D.

Assistant Professor of Pediatrics
University of Michigan Medical School

Stacey Stewart

President and CEO
March of Dimes