



MEMORANDUM

To: Subcommittee on Health Members and Staff
From: Committee on Energy and Commerce Majority Staff
Re: Health Subcommittee Hearing on June 14, 2023

The Subcommittee on Health will hold a hearing on Wednesday, June 14, 2023, at 10:30 a.m. (ET) in 2322 Rayburn House Office Building. The hearing is entitled “Examining Proposals that Provide Access to Care for Patients and Support Research for Rare Diseases.”

I. Witnesses

Panel I

- **Dr. Elizabeth Cherot, MD, MBA**, Senior Vice President and Chief Medical Health Officer, March of Dimes
- **Dr. Alexis A. Thompson, MD, MPH**, Chief of Division of Hematology, Elias Schwartz MD Endowed Chair in Hematology, Children’s Hospital of Philadelphia, Professor of Pediatrics, University of Pennsylvania Perelman School of Medicine
- **Dr. Meredith McNamara, MD, MS, FAAP**, Assistant Professor, Yale School of Medicine
- **Dr. Miriam Grossman, MD**, Child, Adolescent, and Adult Psychiatrist
- **Mr. George Manahan**, Parkinson’s Advocate and Patient
- **Mr. Kevin O’Connor**, Assistant to the General President for Government Affairs and Political Action, International Association of Fire Fighters

II. Background

As the nation’s public health needs continue to increase and evolve, an examination of existing programs is necessary to understand how current programs are utilizing and distributing funding and addressing the public health challenges facing Americans. This hearing will evaluate where gaps exist, identify any potential duplication or redundant efforts, and reveal any improvements needed as Congress considers reauthorizations. The hearing explores several bills addressing various areas of public health, including maternal and children’s health, disease research and prevention, and access to care.

Maternal & Children’s Health

The programs reauthorized under the **Prematurity Research Expansion and Education for Mothers who deliver Infants Early (PREEMIE) Reauthorization Act of 2023** facilitate federal research, education, and intervention activities to reduce preterm birth and infant mortality.

- The U.S. preterm birth rate increased to 10.5 percent in 2021, an increase of four percent since 2020 and the highest recorded rate since 2007.¹ Across the country, 45 states, Washington, D.C., and Puerto Rico experienced an increase in preterm birth rates, while four states saw a decrease.² This means about 1 in 10 infants in the United States are born prematurely each year, or more than 383,000 babies.³
- While there are certain risk factors, preterm birth can happen to any pregnant woman.⁴ Premature babies may face serious⁵ and increased health problems, such as problems with their brain, lungs, heart, eyes and other organs, as well as long-term challenges, intellectual and developmental disabilities.⁶ Though babies born prematurely are more likely to survive than ever before,⁷ preterm birth and its complications remain the second leading cause of infant deaths.
- In 2016, the estimated annual societal economic cost (medical, educational, and lost productivity) associated with preterm birth in United States was \$25.2B.⁷ Individually, the average first year medical costs are about 4 times greater (\$49,140) than for term infants (\$13,024).⁸

The programs reauthorized under the **Preventing Maternal Deaths Reauthorization Act of 2023** assist states in preserving maternal health throughout pregnancy, childbirth, and postpartum and working to better understand the burden of maternal complications and mortality through research, education, best practices, and prevention efforts.

- A maternal death is defined as a death that takes place during pregnancy or within 42 days following delivery. Heart conditions and stroke cause more than 1 in 3 deaths, and risks increase with age and other factors.⁹
- In 2021, 1,205 women died of maternal causes in the United States, compared with 861 in 2020 and 754 in 2019. This reflects an increase of nearly 89 percent in the maternal mortality rate since 2018.¹⁰

¹ 2022 March of Dimes Report Card, <https://www.marchofdimes.org/report-card>.

² 2022 March of Dimes Report Card, <https://www.marchofdimes.org/report-card>.

³ A Profile of Prematurity in the United States, March of Dimes.

<https://www.marchofdimes.org/peristats/reports/united-states/prematurity-profile>

⁴ Preterm labor and premature birth: Are you at risk? March of Dimes, <https://www.marchofdimes.org/find-support/topics/birth/preterm-labor-and-premature-birth-are-you-risk>.

⁵ Waitzman NJ, Jalali A, Grosse SD. Preterm birth lifetime costs in the United States in 2016: An update. *Semin Perinatol.* 2021 Apr;45(3):151390.

⁶ Long-term health effects of premature birth, March of Dimes, <https://www.marchofdimes.org/find-support/topics/birth/long-term-health-effects-premature-birth>.

⁷ Waitzman NJ, Jalali A, Grosse SD. Preterm birth lifetime costs in the United States in 2016: An update. *Semin Perinatol.* 2021 Apr;45(3):151390.

⁸ Medical Costs of Preterm Birth, March of Dimes, <https://www.marchofdimes.org/peristats/data?dv=ls®=99&top=3&stop=362&lev=1&slev=1&obj=1>.

⁹ Maternal death and pregnancy-related death, March of Dimes, <https://www.marchofdimes.org/find-support/topics/miscarriage-loss-grief/maternal-death-and-pregnancy-related-death>.

¹⁰ Maternal Mortality Rates in the United States, 2021, Centers for Disease Control and Prevention, <https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2021/maternal-mortality-rates-2021.htm>.

The **Gabriella Miller Kids First Pediatric Research Program (Kids First)** was created to facilitate additional research and education around the relationship between childhood cancer and structural birth defects, and the shared genetic pathways between these disorders.

- It is estimated that over 9,910 children in the United States under the age of 15 will be diagnosed with cancer in 2023.¹¹ At the same time, one in 33 infants born in the United States has a birth defect. Birth defects are the leading cause of death during the first year of life, and account for half of all pediatric hospitalizations.¹²
- Research has shown that children with birth defects have an increased risk of developing childhood cancer. This suggests there are shared genetic pathways underlying some types of childhood cancer and structural birth defects, though more coordinated research and a better understanding of the role of genetics is needed.

The **Children's Hospitals Graduate Medical Education Program (CHGME)** funds 59 freestanding, children's hospitals in 30 states and Puerto Rico to help their graduate medical education (GME) programs train resident physicians and dentists.

- According to the Health Resources and Services Administration (HRSA), the CHGME program trains 56 percent of all general pediatrics residents and 54 percent of all pediatric subspecialty residents and fellows.¹³
- HRSA found that the national pediatrician supply is estimated to grow by 9 percent by 2025, while the demand is estimated to grow by 6 percent.¹⁴ Reauthorizing the CHGME program will help ensure there is a sufficient supply of pediatricians to meet the expected growth in demand.

Disease Research & Prevention

The programs reauthorized under the **Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023** support states' efforts to provide services, education, training, and best practices related to identification, prevention, and treatment of sickle cell disease.

- Sickle cell disease (SCD) is the most common inherited blood disorder in the United States, affecting an estimated 100,000 Americans.¹⁵ People with SCD are born with it,

¹¹ Key Statistics for Childhood Cancers, American Cancer Society, <https://www.cancer.org/cancer/types/cancer-in-children/key-statistics.html>.

¹² Overview, Gabriella Miller Kids First Pediatric Research Program (Kids First), NIH, <https://commonfund.nih.gov/kidsfirst/overview>.

¹³ Children's Hospital Graduate Medical Education (CHGME) Payment Program, Health Resources and Services Administration, Bureau of Health Workforce, <https://bhw.hrsa.gov/funding/apply-grant/childrens-hospitals-graduate-medical-education>

¹⁴ Health Workforce Projections: General Pediatricians, HRSA Health Workforce, 2017: <https://bhw.hrsa.gov/sites/default/files/bureau-health-workforce/data-research/pediatrician-fs-51817.pdf>

¹⁵ Sickle Cell Disease, National Heart, Lung, and Blood Institute, <https://www.nhlbi.nih.gov/resources/sickle-cell-disease>
<https://www.nhlbi.nih.gov/resources/sickle-cell-disease>

though most newborns who have SCD do not have symptoms until they are about 5 or 6 months old.¹⁶ The majority of SCD patients are Black, and an estimated 1 in 365 Black newborns will have Sickle Cell Disease.¹⁷

- SCD is a lifelong disease, though there are several innovative new medicines to treat the disease, and one cure through a bone marrow or stem cell transplant.¹⁸

The program reauthorized under the **Firefighter Cancer Registry Reauthorization Act of 2023** is intended to build upon current work and fill in the knowledge gaps of the current national cancer registry, which is a voluntary online enrollment system to help support and understand the link between cancer and the fire service.

- Between 2010 and 2015, the National Institute for Occupational Safety and Health (NIOSH) launched the largest study of American firefighters ever taken. A multi-year study, the goal was to examine whether firefighters have a higher risk of cancer and other causes of death due to job exposures. The study examined both deaths from cancer, as well as the specific type of cancer diagnosis.¹⁹
- The study found a greater number of cancer diagnoses and cancer-related deaths amongst firefighters. The highest prevalence was digestive, oral, respiratory, and urinary cancers. There were also more cases of certain cancers among younger fire fighters than would otherwise be expected.²⁰

The **National Plan to End Parkinson's Act** will take efforts to coordinate a federal response to support research, care, and services to manage, treat, and cure Parkinson's Disease, including initiating a national plan, issuing recommendations, and establishing an Advisory Council.

- It is estimated that Parkinson's disease (PD) affects nearly 1 million people in the United States and more than 6 million people worldwide.²¹ It is the second most common neurological disease globally with nearly 90,000 new cases diagnosed every year.
- The cause of Parkinson's remains largely unknown, though it is likely a combination of genetic and environmental factors. While there is no cure, treatment options vary and include medications, lifestyle adjustments, and surgery.²²

¹⁶ Sickle Cell Disease, National Heart, Lung, and Blood Institute, <https://www.nhlbi.nih.gov/resources/sickle-cell-disease>.

¹⁷ About Sickle Cell Disease, Sickle Cell Disease Partnership, <https://www.sicklecellpartnership.org/about-sickle-cell-disease/>.

¹⁸ Sickle Cell Disease, National Heart, Lung, and Blood Institute, <https://www.nhlbi.nih.gov/resources/sickle-cell-disease>; About Sickle Cell Disease, Sickle Cell Disease Partnership, <https://www.sicklecellpartnership.org/about-sickle-cell-disease/>.

¹⁹ Firefighter Resources, Cancer and Other Illnesses, Centers for Disease Control and Prevention, <https://www.cdc.gov/niosh/firefighters/health.html>.

²⁰ Findings from a Study of Cancer among U.S. Fire Fighters, Centers for Disease Control and Prevention, <https://www.cdc.gov/niosh/pgms/worknotify/pdfs/ff-cancer-factsheet-final-508.pdf>.

²¹ Parkinson's 101, Michael J. Fox Foundation, <https://www.michaeljfox.org/parkinsons-101>.

²² What is Parkinson's?, Parkinson's Foundation, <https://www.parkinson.org/understanding-parkinsons/what-is-parkinsons>.

- The estimated total cost of Parkinson’s disease to individuals, families and the United States government is estimated to be about \$51.9 billion every year, with \$25.4 billion attributable to direct medical costs (e.g., hospitalizations, medication) and \$26.5 billion in non-medical costs like missed work, lost wages, early forced retirement and family caregiver time. According to a recent study, the federal government spends nearly \$25 billion annually in caring for people with Parkinson’s. About \$2 billion of that is shouldered by Social Security, and the remaining \$23 billion is in Medicare costs since an estimated 90 percent of people with PD receive Medicare benefits.²³

Access to Care

The program reauthorized under the **Action for Dental Health Act of 2023** assists states taking innovative steps to address the dental workforce needs.

- Over 1 in 4 adults have untreated tooth decay and almost half of adults 30 years or older show signs of gum disease.²⁴ Although dental health care outcomes have greatly improved over the years, there are still gaps that need to be addressed to help improve education and access to care.

III. Legislation

H.R. 3226, the PREEMIE Reauthorization Act of 2023 (Reps. Anna Eshoo, Mariannette Miller-Meeks, Robin Kelly, Jen Kiggans, Lisa Blunt Rochester, and Michael Burgess)

H.R. 3226 would reauthorize the Prematurity Research Expansion and Education for Mothers who deliver Infants Early Act for fiscal years 2024-2028. This reauthorization would include the renewal of research, education, and intervention activities and programs at the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) that focus on preventing preterm births and reducing infant mortality. The bill would also authorize a new study on the financial costs of premature births to society, among other things.

H.R. 3838, the Preventing Maternal Deaths Reauthorization Act of 2023 (Reps. Michael Burgess, Diana DeGette, Buddy Carter, Robin Kelly, Kat Cammack, and Kathy Castor)

H.R. 3838 would reauthorize federal support for states to address disparities in maternal health outcomes and preserve the health of mothers during pregnancy, childbirth, and the postpartum period for fiscal years 2024-2028. This legislation would also require the CDC to work in consultation with the HRSA to disseminate best practices relating to the prevention of maternal mortality to hospitals and other health care providers.

H.R. 3843, the Action for Dental Health Act of 2023 (Reps. Robin Kelly and Mike Simpson)

²³ Parkinson’s Disease Economic Burden on Patients, Families and the Federal Government Is \$52 Billion, Doubling Previous Estimates, Michael J. Fox Foundation, <https://www.michaeljfox.org/publication/parkinsons-disease-economic-burden-patients-families-and-federal-government-52-billion>.

²⁴ Centers for Disease Control and Prevention, Adult Oral Health, Facts About Adult Oral Health, <https://www.cdc.gov/oralhealth/basics/adult-oral-health/index.html>

H.R. 3843 would reauthorize grants under HRSA to address dental workforce needs for fiscal years 2024-2028.

H.R. 3884, the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023 (Reps. Michael Burgess, Danny Davis, and Buddy Carter)

H.R. 3884 would reauthorize the program and activities under CDC and HRSA providing for sickle cell disease and other heritable blood disorders, research, surveillance, prevention, and treatment, for fiscal years 2024-2028.

H.R. 3821, the Firefighter Cancer Registry Reauthorization Act of 2023 (Reps. Bill Pascrell, Brian Fitzpatrick, Steny Hoyer, and Mike Bost)

H.R. 3821 would reauthorize funding for the voluntary registry for firefighter cancer incidents under the CDC for fiscal years 2024-2028.

H.R. 2365, the National Plan to End Parkinson's Act (Reps. Gus Bilirakis and Paul Tonko)

H.R. 2365 would direct the HHS Secretary to coordinate federal efforts and carry out a national review, assessment, plan, and strategy that involves activities related to the prevention, management, treatment, and cure of Parkinson's Disease. The bill would also require HHS to establish an advisory council to evaluate current efforts, issue recommendations, and evaluate the national plan and strategy related to Parkinson's Disease.

H.R. 3391, the Gabriella Miller Kids First Research Act 2.0 (Reps. Jennifer Wexton, Tom Cole, Debbie Dingell, and Gus Bilirakis)

H.R. 3391 would reauthorize funding for the National Institute of Health's (NIH) Gabriella Miller Kids First Pediatric Research Program. The bill also requires coordination of federal efforts related to pediatric cancer research, as well as a report detailing current federally funded programs and initiatives, and the advancements made.

H.R. 3887, the Children's Hospital GME Support Reauthorization Act of 2023 (Rep. Dan Crenshaw)

H.R. 3887 would reauthorize payments to children's hospitals that operate Graduate Medical Education programs and prohibit payments to children's hospitals that conduct surgeries or prescribe puberty blockers and/or hormone therapies to minors for the purposes of gender affirming care. The program is reauthorized for fiscal years 2024-2028.

H.R. 3836, the Medicaid Primary Care Improvement Act (Reps. Dan Crenshaw, Kim Schrier, Lloyd Smucker, and Earl Blumenauer)

H.R. 3836 would clarify that Medicaid can provide direct primary care to Medicaid beneficiaries.

IV. Staff Contacts

If you have questions regarding this hearing, please contact Molly (Brimmer) Lolli, Kristin Flukey, or Seth Gold of the Committee staff at 202-225-3641.