

## Congressman Brett Guthrie Opening Statement

*As Prepared for Delivery*

**06/14/23**

Today we are here to discuss legislation to promote access to care and improve health outcomes for Americans...

We'll consider bills to help support the work being done by American innovators who develop therapies and live-saving cures for rare diseases, which effect more than 30 million Americans.

We'll also consider legislation to help the American health care system improve outcomes for vulnerable populations like pregnant and postpartum women, children, patients, and the brave men and women in the fire service.

Nothing means more to parents than protecting the health and well-being of their children. That is why we are considering H.R. 3391, the *Gabriella Miller Kids First Research Act 2.0*, which would reauthorize the National Institutes of Health's (NIH) Gabriella Miller Kids First Pediatric Research Program. This program is deepening the research community's understanding of the relationship between rare cancers and other birth defects, helping foster the development of best treatment practices and therapeutics, and improving the lives of kids and their families living with these conditions.

We're also considering H.R. 3226, the *PREEMIE Reauthorization Act of 2023*, led by Ranking Member Eshoo and Representatives Miller-Meeks, Kelly, Kiggans, Blunt Rochester, and Burgess. This legislation will continue work being conducted at the CDC to identify best practices that promote healthy pregnancies and avoid preterm births. According to the CDC, preterm babies and those with low birth weights attributed to 16% of infant deaths under 1 year of age in 2020. We must do better to reduce preterm births and improve health outcomes for these babies.

We also have more work to do to protect the long-term health and well-being of our expecting and new moms by continuing to build off the work this subcommittee has done over the past several years to address maternal mortality. In 2021, CDC data showed over 1,200 women died from maternal causes, which is up from 861 in 2020 and from 754 in 2019. These numbers demonstrate a staggering need for continued work to address risky pregnancies. H.R. 3838, the *Preventing Maternal Deaths Reauthorization Act*, will continue the work done by the CDC and HRSA to provide access to resources for women experiencing risky pregnancies and develop best practices to treat at-risk moms.

Our first responders also experience adverse health outcomes often resulting from the selfless and brave work they do to keep us and our loved ones safe. Sadly, cancer diagnoses and deaths are higher for firefighters than national cancer rates, especially for bladder, esophageal, leukemia, and other types of cancer. H.R. 3821, the *Firefighter Cancer Registry Reauthorization Act*, will reauthorize this registry and enhance our understanding of the causes of these high cancer rates, with the goal of reducing cancer diagnoses and deaths.

We're also examining legislation to advance our knowledge of rare diseases and promote access to therapies to treat these diseases, such as sickle cell and other heritable blood disorders and and

Parkinson's Disease. These conditions are life-threatening, and currently lack a wide range of treatment options. These conditions can also be very costly for patients and for the health care system. It is estimated to cost roughly \$1.7 million per patient for the lifetime costs of treating a sickle cell patient. Likewise, the total cost of Parkinson's Disease to individuals, families, and the U.S. government is estimated to be nearly \$52 billion every year. As a step forward to address these issues, today we are examining both H.R. 3884, the *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act*, and H.R. 2365, the *National Plan to End Parkinson's Act* I would like to thank Representatives Burgess and Bilirakis for their leadership on these bills.

Fortunately, we are already seeing progress and breakthroughs in treatments for these and a variety of other rare diseases. That is why I am proud to be leading legislation with Ranking Member Eshoo that already passed this committee, the *MVP Act*, which would provide further access to life-changing treatments to patients living with heartbreaking, and currently incurable, diseases.

Lastly, we are considering H.R. 3887, the *Children's Hospital GME Support Reauthorization Act of 2023*. This program provides funding to children's hospitals to help train resident physicians and dentists. It's critical for us to reauthorize the program before the end of the fiscal year with necessary policy changes to keep kids safe from experimental procedures.

In closing, I am proud of the many bipartisan bills before us that will improve access to care and drive innovation. Patients and their families will be better off because of the work we are doing today. Thank you, and I yield back.