

Testimony to the Joint Legislative Budget Hearing on Health
on the subject of Newborn G6PD Deficiency Screening in New York State

Submitted by:
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Thank you for the opportunity to provide testimony. I am the President and Founder of the New York-based G6PD Deficiency Foundation, a 501-c3 nonprofit organization that aims to provide education, support and resources to those affected by G6pd deficiency, their caregivers and medical professionals.

G6PD Deficiency (G6PDd) is an enzyme deficiency that is passed on genetically to infants via the X chromosome. Infants to whom this deficiency is passed are at risk of developing severe hemolysis (the destruction of healthy red blood cells) when their bodies are subjected to increased levels of oxidative stress. Certain triggers increase oxidative stress levels in all individuals afflicted with G6PDd. Among those items identified as triggers are certain infections, medications, chemicals & food.

At birth, infants who are afflicted with this enzyme deficiency may develop an advanced form of jaundice known as hyperbilirubinemia and if not treated, the G6PD deficient infant is vulnerable to kernicterus, a type of brain damage. Without point-of-care quantitative screening, an undetected G6PD deficient newborn may be sent home while hyperbilirubinemia is developing. The knowledge of an infant's status while still in the hospital can allow for proper treatment and education, and most importantly, prevention of serious health damage.

For those who live with with the effects of kernicterus, the cost of treatments, therapies and assistance with daily living can equate to \$25 million to \$30 million over that individual's lifetime. Comparatively, brain damage caused by kernicterus is similar to that suffered by an individual afflicted with Cerebral Palsy. Anecdotally, these figures conform to the cost associated with care and treatment of Brody Harris, a G6PD deficient individual who developed kernicterus, and my grandson.

By testing for G6PD deficiency at birth, the incidence of kernicterus in G6PD deficient infants will be significantly decreased. Commensurately, G6PD deficiency will be considered in the differential diagnosis of clinicians, a fact that will most certainly improve the treatments and outcomes of all G6PD deficient patients at every age. If patients know about the deficiency and further understand what triggers to avoid, hospitalizations arising from G6PD deficiency complications will certainly decrease. The cost of one G6PD deficiency test may save millions of dollars in medical care.

My grandson developed kernicterus shortly after his birth due to an undiagnosed G6PD deficiency and suffered irreversible brain damage that could have been prevented by universal newborn screening. This inspired me to start this foundation and become an advocate for others like him. For the past 4 years, our foundation has been advocating for a bill in Albany that would add G6PD deficiency to New York's battery of universal screenings performed on newborns. Last year's bill (S6542/A7338) passed the legislature unanimously but was vetoed (Veto Message #143) by the Governor due to funding concerns.

The World Health Organization recommends universal screening if the incidence of the disease affects 3% or more of the male population and the prevalence of G6PD deficiency is estimated at between 4-7% in the United States, falling within the recommended threshold for screening. Those who have G6PD deficiency can live completely healthy lives once aware of their condition and educated on which stressors, medications and foods they need to avoid to prevent hemolysis. The earlier patients can be screened, the less complications and costs will occur.

To achieve this, we are asking for the passage of universal, point-of-care quantitative screening for infants across New York State and a budget allocation of \$3 million for the testing itself, as estimated by the Governor's office in her veto message, and \$2 million for a public education and awareness campaign, something the Governor suggested in the veto message.

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