



DATE: March 5, 2020 **COMMITTEE:** Senate Finance
BILL NO: Senate Bill 879
BILL TITLE: Public Health – Maryland Infant Lifetime Care Trust Funded by HSCRC and Maryland Patient Safety Center Duties
POSITION: Support

Kennedy Krieger Institute supports Senate Bill 879 - Public Health – Maryland Infant Lifetime Care Trust Funded by HSCRC and Maryland Patient Safety Center Duties

Bill Summary:

This legislation establishes the Infant Lifetime Care Trust. The trust will be funded by hospitals who deliver babies and would provide guaranteed lifetime care for infants injured at birth.

Background:

Kennedy Krieger Institute is an internationally recognized institution dedicated to improving the lives of children and adults with developmental disabilities and disorders of the brain, spinal cord and musculoskeletal system. KKI serves over 24,000 patients per year throughout their life spans, many of whom have a history of perinatal brain injury.

The Infant Neurodevelopment Center at Kennedy Krieger specializes on follow-up of high risk infants including those with devastating brain injury in the perinatal period. We see around 500 children a year, following them from hospital discharge through preschool years, and provide neurodevelopmental consults in the Neonatal Intensive Care Units at Johns Hopkins.

A key piece of our practice is guiding parents through appropriate support as new developmental concerns arise. We provide comprehensive, multi-disciplinary assessments at key points when best prognostication is available for disability such as cerebral palsy, intellectual disability, cortical vision impairment, autism, learning disability and ADHD.

Infants with severe perinatal brain injury can require a number of specialized services for ongoing medical and developmental care:

- Gastrostomy tubes (for problems of the mouth, stomach, esophagus or intestines)
- Supplemental oxygen
- Durable medical equipment, braces, wheelchairs and augmentative communication devices
- Targeted therapies, most commonly physical therapy, occupational therapy and speech language therapy
- Supports and accommodations including nursing care and school accommodations.

Each of these supports is targeted to a particular need and those needs change over time, requiring ongoing, serial assessment to tailor the child's treatment plan.

Rationale:

The Maryland Infant Lifetime Care Trust is important for the overall health of the children it would serve because it allows for the family and treating physician to provide appropriate support to the children when they need it based on thorough individualized assessment rather than on prognostication of the future.

Children's needs change as they grow and age. Support needs that are appropriate at younger ages may not be appropriate at older ages. Similarly, additional needs may surface throughout a patient's life that may require new therapies unforeseen at infancy or childhood.

Finally, we are at an exciting time in perinatal brain injury medicine with new targeted therapies for complications of perinatal brain injury such as cerebral palsy that are changing outcomes, which makes it increasingly difficult to predict outcomes at a single point in time; the pace of change requires ongoing, lifelong evaluations to determine appropriate care. Treating physicians and families need a reasonable way forward that allows children with severe perinatal brain injury to receive fully-compensated, targeted, timely and individualized lifetime care to address the children's ever-changing needs. The Infant Lifetime Care Trust would guarantee that care.

Kennedy Krieger Institute requests a favorable report on Senate Bill 879.