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THE MARYLAND HOUSE OF DELEGATES

ANNAPOLIS, MARYLAND 21401

Testimony in Support of HB 1563 Public Health—Maryland Infant Lifetime Care Trust Funded by HSCRC and Maryland Patient Safety Center Duties.

Good afternoon Chair Clippinger, Vice Chair Atterbeary and members of the Judiciary Committee. I am here to introduce House Bill 1563 **Public Health—Maryland Infant Lifetime Care Trust Funded by HSCRC and Maryland Patient Safety Center Duties.**

I am passionate about this *new* bill. Not only does it address all the criticisms that have been raised in the past about a similar bill, it provides benefits to the State, and most importantly, to infants injured at birth and their families. Now is the time to act on this very important piece of legislation.

There are many reasons to pass this legislation, but for me the fact that it directly supports the individuals who are living with the impact of neurological birth injury—not the just the child, but the family. It provides assurance that medical needs will be funded; it incorporates the families and their chosen physicians into life planning. That planning will be designed to help the individual—the child—overcome, and maybe even remove some barriers, so their quality of life can be maximized. The costs for the supports in those plans are high—and on-going through the life of the person.

Consider for a moment what might be needed; the list below does not begin to be exhaustive; it only touches the surface:

Equipment:

- Wheelchairs that need to be upgraded at least every 5 years
- Walkers
- Air concentrators
- Supplies for feeding tubes and catheterization
- Diapers
- Augmentative speech devices

Accessibility

- Housing with appropriate ramps and spaces
- Transportation
- Physical access to all the rooms

Supportive Services:

- Occupational therapy

- Physical Therapy
- Speech Therapy
- Assistive nursing care

There is simply no way to predict what care and services will serve an individual child the best when they are young. As a career special educator I have actually witnessed miracles; through the provisions of services and appropriate equipment, children who were “written off” become engaged, interactive and even get jobs. How much money will be needed to facilitate those miracles is unpredictable. These miracles should not be available to just those with resources and that is what the Trust will guarantee through its payment for the elements that the person needs to reach high levels of engagement. These things are costly—and ongoing through the life of the individual.

There is no question that infants with birth injuries should be guaranteed the care they need – for life. But today’s system doesn’t provide that guarantee. Instead, to cover the cost of care, families have to rely on a jury’s estimate or a lawyer’s agreement of what will be needed to care for the complex, lifelong health challenges of an infant with birth injuries. Contrary to the current system of upfront payments, based on estimations with no evidence for potential, these costs would be covered in real time.

Under the current system, in some cases, this estimate may be too little and families could face serious strain if the money runs out before the child’s needs do. No family should have to run fundraisers in order to afford lifelong healthcare needs for their children, and nobody should have to jump through hoops to access necessary care – from diapers to medicines to therapy – for their child. The Infant Lifetime Care Trust would guarantee they never would.

In other cases, the estimate will be too much and astronomical awards will destabilize the healthcare system in Maryland, leading to higher costs for all and impacting the availability of maternity care in our state. The Infant Lifetime Care Trust would guarantee stability to Maryland’s hospital insurance premiums and prevent the current crisis from deepening. The Maryland Infant Lifetime Care Trust is a new, common-sense approach that is right for families, for infants, and for Maryland.

The Trust turns today’s guess—a lump sum payment that may or may not be sufficient—into a guarantee of lifetime care directed by the family’s own chosen physician. Permanently funded through assessments on hospitals, the Trust would provide guaranteed lifetime care for infants born with neurological injuries. And if a mistake has been made, hospitals remain accountable to those families. A family’s right to a jury trial would remain unchanged. This is a better way than our current system.

As we all know, caring for a chronic condition requires more than medical care and doctors’ visits. The Trust would pay not only for medical treatment but also for other expenses necessary for the lifetime care of the child. It would pay for transportation costs, physical, behavioral and specialty therapies, including home modifications, and other services that a family and their chosen doctor deem is necessary.

And, the Trust would lead to savings in Maryland's Medicaid system. Maryland's Medicaid system would no longer be responsible for paying for the care of these children. Under the current system, Medicaid is often financially responsible for the medical care of children born with neurological injuries. Under this proposal, the Trust would pay for all care currently covered by Medicaid, and cover care and services that are currently not allowed to be paid for by Medicaid.

You are going to hear today from several experts regarding:

- Rising medical liability costs and the serious destabilization of the hospital reinsurance market.
- Concerns about the training, recruitment, and retention of OB doctors and access to critical OB services.
- How it is very difficult to accurately predict future care costs in these rare, complex cases.
- The mechanics of the bill, how it works to provide guaranteed lifetime care without major changes to the tort system.
- How the State of New York has successfully enacted and implemented a similar model.

These experts will be able to clearly articulate the nuances of this problem and how thoughtfully this solution has been created. Unfortunately, the issues addressed in this bill, specifically the volatility of the medical liability market and the uncertainty of the cost of life time care for an infant with a neurological injury, are not going away. If a solution is not implemented, the consequences could be detrimental to the accessibility of medical care in Maryland. This is the innovative, commonsense solution we have been waiting for.

Finally, I want to remind the committee that this is a new bill and a new commonsense approach to medical liability. This new bill—the Infant Lifetime Care Trust – was designed specifically to address the concerns of the opposition. It allows access to the courts so patients may seek their justice, it does not change attorney's fees calculations, and most importantly it creates a family-friendly process to guarantee full access to all benefits. If the family's physician doctor orders a new treatment, equipment, or anything that child may need, it is automatically presumed to be a valid health care cost under this new approach.

As Maryland's duly elected representatives, we have an important opportunity before us. We can provide six guarantees to the families, infants, and patients of Maryland:

- A guarantee of care for life.
- A guarantee of permanent solvency of the fund.
- A guarantee of physician-directed benefits.
- A guarantee of family access to benefits on demand.
- A guarantee of long-term decreases in Medicaid spending.
- And a guarantee of improving Maryland's ability to attract and retain OB-GYNs to serve our communities.

For all these reasons, I request a favorable report on House Bill 1653 Public Health—Maryland Infant Lifetime Care Trust Funded by HSCRC and Maryland Patient Safety Center Duties.