March 18, 2025

The Honorable Glenn A. Youngkin
Governor Commonwealth of Virginia
1111 East Broad Street, 3rd Floor
Richmond, VA 23219

Re: HB 1782 – Newborn Screening Legislation

Dear Governor Youngkin:

As patient advocacy organizations representing individuals and families diagnosed with rare diseases in Virginia, we write to ask you to sign HB 1782, legislation that would ensure Virginia continues to be a leader in the Nation on Newborn Screening.

For more than 50 years, nearly every newborn in the U.S. has been screened for a range of medical conditions that, if left untreated, can cause disabilities, developmental delays, serious illness, or even death. These simple screens, which rely on just a few drops of blood from a newborn's heel, can provide identification of these serious conditions before it is too late to receive treatment.

Screening at birth for pediatric-onset conditions that are known to be devastating if not acted upon provides the following benefits to Virginia families:

- Providing earlier access to supportive therapies and treatment.
- Reducing or eliminating expensive and unnecessary services, tests, and treatments.
- Preventing deaths and delaying disease complications and physical disabilities.
- Enabling opportunities to evaluate future family planning based on diagnosis.

The process to add new conditions to a state's newborn screening panel typically starts after is has been recommended for inclusion on the Recommended Uniform Screening Panel (RUSP). The RUSP is a list of 38 disorders recommended for states to screen for by the U.S. Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) and approved by the U.S. Secretary of Health and Human Services. New conditions are nominated to the RUSP by patient organizations and are added through science-driven, evidence-based review processes. Committee members recommend disorders to the RUSP based on evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments.

Although this recommendation is made, it is the sole discretion of each state which conditions are included in their Newborn Screening Panel. HB 1782 would ensure Virginia's robust, autonomous review and decision-making process is protected.

Serving the Commonwealth directly, Virginia's Newborn Bloodspot Screening Program (VNBSP) is a partnership between the Virginia Division of Consolidated Laboratory Services and the Virginia Department of Health that performs more than 4 million newborn screening tests a year. In addition to sample collection and testing, the program consists of educational materials for parents, training for healthcare professionals, and follow-up services. The program is funded by newborn screening fees, which are billed to hospitals or medical care providers and are covered by public and private insurance.

We are very proud to say HB 1782 is the result of a collaborative process between patient advocacy groups, the Virginia Department of Health, the Virginia Division of Consolidated Laboratory Services, the

Virginia Hospital & Healthcare Association, and the Virginia Association of Midwives. This legislation would:

- Codify existing practices in the VNBSP that have proven to be effective.
- Create a streamlined process for Virginia health officials and the legislature to work together to review new RUSP conditions while also ensuring Virginia is the decision maker, not the federal government.
- Provide Virginia families with a transparent timeline for the Commonwealth to make its decision.

This bill empowers Virginia to continue its tradition of thoughtful, independent decision-making in healthcare. It allows us to evaluate and implement screening recommendations that are most appropriate for our population, ensuring that our healthcare system remains responsive and effective. By considering RUSP recommendations while maintaining our state's discretion, we can provide the best possible outcomes for Virginians.

We ask you to sign HB 1782 and look forward to working with you to ensure that Virginia's newborns have access to life-changing and potentially life-saving diagnoses.

Sincerely,

AKARI Foundation
Association for Creatine Deficiencies
Australian Pompe Association Inc.
BARE Inc. (Biliary Atresia Research and Education)
Boomer Esiason Foundation
Cure GM1 Foundation
Cure Sanfilippo Foundation
Cystic Fibrosis Research Institute
EveryLife Foundation for Rare Diseases
Foundation for Angelman Syndrome Therapeutics
Foundation for Prader-Willi Research
Friedreich's Ataxia Research Alliance (FARA)
Gene Giraffe Project
GRIN2B Foundation
HCU Network America
Hunter Syndrome Foundation
Hunter's Hope Foundation
Immune Deficiency Foundation
International Foundation for CDKL5 Research
International MPS Network
KrabbeConnect
Leukodystrophy Newborn Screening Action Network
MLD Foundation
MTM-CNM Family Connection
National Ataxia Foundation
National Fabry Disease Foundation
National MPS Society
National Niemann Pick Disease Foundation (NNPDF)
National PKU Alliance
National Tay-Sachs & Allied Diseases Association
Organic Acidemia Association
Parent Project Muscular Dystrophy
Pompe Alliance
Prader-Willi Syndrome Association, USA
Project Alive
Project GUARDIAN
Rare And Black
Rare And Undiagnosed Network
Rare Disease Innovations Institute, Inc.
T.E.A.M. 4 Travis (Together Ending Asplenia Mortality)
The Global Foundation for Peroxisomal Disorders
The Network of Tyrosinemia Advocates
TSC Alliance
United MSD Foundation