May 5, 2025

Robert F. Kennedy Jr.
Secretary, Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Kennedy,

On behalf of the 272 undersigned organizations committed to the health of our nation's mothers, infants, children, and families, we express our deep concern over the Administration's recent decision to eliminate the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC). This sudden termination, alongside the proposed elimination of other federal newborn screening infrastructure, will delay time-sensitive detection of serious medical conditions in newborns and will impede delivery of clinical care and intervention to babies with devastating, treatable conditions during the optimal therapeutic window. We urge you to immediately reinstate the work of this important federal advisory committee and preserve our nation's federal newborn screening infrastructure.

Newborn screening is one of our nation's most successful public health programs, serving nearly 4 million infants each year and saving thousands of babies' lives. Our nation's newborn screening system detects life-threatening diseases in newborn babies before they can cause irreversible damage or death. Through timely detection and treatment within the first few days of life, our national newborn screening program provides American children the best chance at a healthy life — a purpose that aligns with the Administration's vision for a healthier America.

The ACHDNC is a critical part of the U.S. newborn screening system, providing guidance to the Secretary of the Department of Health and Human Services (HHS) on the most appropriate application of universal newborn screening tests, technologies, policies, guidelines, and standards. The Health Resources and Services Administration (HRSA), the National Institutes of Health (NIH), the Food and Drug Administration (FDA), and the Centers for Disease Control and Prevention (CDC) all provide guidance to the ACHDNC from their specific expertise, with the ACHDNC serving as the convenor and the central point of contact for all federal agencies and the newborn screening community overall. The proposed elimination of newborn screening programs across the federal agencies would significantly limit the expertise available both within the federal government and to state newborn screening programs. These programs provide grant funding, make recommendations, and track the impact of newborn screening to help improve health outcomes.

Policymakers created the ACHDNC through a bipartisan effort to bring uniformity to the U.S. newborn screening system as part of the Newborn Screening Saves Lives Act, passed by Congress in 2007 and signed into law in 2008. Prior to the passage of the bill, only 10 states and the District of Columbia required infants to be screened for all 29 disorders recommended for screening by the American College of Medical Genetics and Genomics. Today, all 50 states and the District of Columbia require screening for at least 32 treatable conditions. The ACHDNC has served as the nation's chief newborn screening advisory body under Democrat and Republican administrations alike, making newborn screening one of the most successful public health programs in the country.

The ACHDNC plays an instrumental role in the maintenance of the Recommended Uniform Screening Panel (RUSP), a list of disorders that the Secretary recommends states to screen for as part of their universal newborn screening program. The ACHDNC oversees the evaluation of conditions considered for addition to the RUSP, reviewing and assessing the clinical and health outcomes of early detection and treatment and the readiness of the public health system to expand newborn screening. While states determine which conditions are screened as part of their respective programs, many states have limited resources to review evidence, and it is not feasible for all 50 states to conduct their own evidence review for every condition. The addition of new conditions to the RUSP guides the expansion of newborn screening at the state level, enabling early detection and treatment of serious rare disorders and saving thousands of lives.

The ACHDNC supports individual states' decision-making processes for adding conditions to their newborn screening panel, providing an evidence review that can be evaluated and implemented in every single state. The Committee's work guides federal recommendations that protect our nation's newborns from preventable death, enabling timely clinical interventions and optimized health outcomes. There is no comparable body to carry out this function in its absence. Without a clear path forward, the Administration's elimination of this committee risks the preventable death and suffering of children with treatable rare disorders.

We strongly urge you to preserve our federal newborn screening system and reinstate the work of the ACHDNC immediately so dedicated experts can continue to guide the lifesaving work of our nation's newborn screening programs without any further delay.

Sincerely,

Achalasia Awareness Organization
Acid Maltase Deficiency Association (AMDA)
ADCY5.org
Adrenal Insufficiency United
Adult Polyglucosan Body Disease (APBD) Research Foundation
Advocate Health
Akari Foundation
Akron Children's Hospital
Alabama Rare Disease Advisory Council
Alaska Chapter, American Academy of Pediatrics
ALD Alliance/Newborn Screening Alliance
Alliance for Regenerative Medicine
Alpha-1 Foundation
Alport Syndrome Foundation
Ambry Genetics
American Academy of Allergy, Asthma & Immunology
American Academy of Neurology
American Academy of Ophthalmology
American Academy of Pediatrics
American Association for Pediatric Ophthalmology and Strabismus
American College of Allergy, Asthma and Immunology

American College of Medical Genetics and Genomics
American College of Obstetricians and Gynecologists
American Society for Clinical Pathology
American Society for Reproductive Medicine
American Society of Hematology
American Society of Human Genetics
Angelman Syndrome Foundation
Ann & Robert H. Lurie Children's Hospital of Chicago
Aplastic Anemia and MDS International Foundation
Arizona Chapter, American Academy of Pediatrics
Association for Creatine Deficiencies
Association for Diagnostics & Laboratory Medicine
Association of Public Health Laboratories
Autoimmune Association
Autoimmune Encephalitis Alliance, Inc.
Avery's Hope
Ayana's Hope Cells
BDSRA Foundation
Bionano Genomics, Inc.
Bionano Laboratories
Bloom Syndrome Association
Boomer Esiason Foundation
Bubba's Light, Inc.
CACNA1A Foundation
California Chapter 1, American Academy of Pediatrics
California Chapter 3, American Academy of Pediatrics
California Life Sciences
California Rare Disease Access Coalition Hemophilia Council of California
Chiesi Global Rare Diseases
Child Neurology Foundation
Children's Craniofacial Association
Children's Hospital Colorado
Children's Hospital of Orange County (CHOC)
Children's Sickle Cell Foundation, Inc.
Chondrosarcoma CS Foundation, Inc.
Coalition to Cure Calpain 3
Coffin-Lowry Syndrome Foundation
Colorado Chapter, American Academy of Pediatrics
Colorado Rare Disease Advisory Council
COMBINEDBrain, Inc.
Congenital Adrenal Hyperplasia Research, Education & Support Foundation
Connetics Consulting, LLC
CTNNB1 Connect & Cure
CTX Alliance

CureARS
Cure 4 The Kids Foundation
Cure CMD
Cure GM1 Foundation
Cure LGMD2i Foundation
Cure SMA
cureCADASIL
CureSHANK
Cyclic Vomiting Syndrome Association
Cystic Fibrosis Foundation
Cystic Fibrosis Research Institute
Cystinosis Research Network
Dana's Angels Research Trust
Danny's Dose Alliance
debra of America
District of Columbia Chapter, American Academy of Pediatrics
DLG4 SHINE Foundation
Dravet Syndrome Foundation
Dup15q Alliance
Elpida Therapeutics
Eosinophilic & Rare Disease Cooperative
EveryLife Foundation for Rare Diseases
Fabry Support & Information Group
FACES: The National Craniofacial Association
Familial Dysautonomia Foundation
Firefly Fund
flok Health
Florida Chapter of the American Academy of Pediatrics, Inc.
Foundation for Angelman Syndrome Therapeutics
Foundation to Fight H-abc
Friedreich's Ataxia Research Alliance (FARA)
Galactosemia Foundation
Gaucher Community Alliance
Gene Giraffe Project
GeneDx
Genetic Alliance
Global Genes
Global Liver Institute
Grant's Giants Pompe Awareness Nonprofit
Greenwood Genetic Center
GRIN2B Foundation
Haystack Project
HCU Network America
Histiocytosis Association, Inc.

HNRNP Family Foundation
Hope in Focus
Hues for Hope
Hydrocephalus Association
Hypertrophic Cardiomyopathy Association
Idaho Chapter, American Academy of Pediatrics
Illinois Chapter, American Academy of Pediatrics
Immune Deficiency Foundation
Indiana Chapter, American Academy of Pediatrics
Indiana Rare Disease Advisory Council
Institute for Gene Therapies
International Foundation for CDKL5 Research
International Society for Mannosidosis & Related Diseases (ISMRD)
Iowa Chapter, American Academy of Pediatrics
Jett Foundation
Johns Hopkins All Children's Hospital
Kansas Chapter, American Academy of Pediatrics
Kentucky Chapter, American Academy of Pediatrics
Key Proteo
Kids Conquering Sickle Cell Disease Foundation
KIF1A.org
KrabbeConnect
Krishnan Family Foundation
Labcorp
Little Hercules Foundation
Little Miss Hannah Foundation
Louisiana Chapter, American Academy of Pediatrics
Louisiana Rare Disease Advisory Council
Lupus and Allied Diseases Association, Inc.
Maine Chapter, American Academy of Pediatrics
Malan Syndrome Foundation
Maple Syrup Urine Disease Family Support Group
March of Dimes
Marshall's Mountain, Inc.
Maryland Chapter, American Academy of Pediatrics
M-CM Network
MedGenyx, PLLC
Michele Schoonmaker, LLC
Michigan Chapter, American Academy of Pediatrics
Michigan Medicine
Michigan Rare Coalition
Michigan Rare Disease Advisory Council
Minnesota Chapter, American Academy of Pediatrics
Minnesota Rare Disease Advisory Council

Mississippi Chapter, American Academy of Pediatrics
Mississippi Metabolics Foundation
Mississippi Rare Disease Advisory Council
MitoAction
MLD Foundation
MPS SuperHero Foundation
MTS Sickle Cell Foundation, Inc.
Muenzer MPS Research & Treatment Center
Muscular Dystrophy Association
Myasthenia Gravis Foundation of America
MyOme
Myositis Support and Understanding
Myotonic Dystrophy Foundation
National Adrenal Diseases Foundation
National Association of Pediatric Nurse Practitioners
National Ataxia Foundation
National CMV Foundation
National Health Council
National MPS Society
National Niemann Pick Disease Foundation
National Organization for Rare Disorders
National PKU Alliance
National Society of Genetic Counselors (NSGC)
National Tay-Sachs & Allied Diseases Association, Inc.
Nationwide Children's Hospital, Columbus, Ohio
Necrotizing Enterocolitis (NEC) Society
Nemours Children's Health
Nevada Chapter, American Academy of Pediatrics
Nevada Rare Disease Advisory Council
New Hampshire Chapter, American Academy of Pediatrics (NHAAP)
New Mexico Pediatric Society
New York State Department of Health
New York State Chapter 2, American Academy of Pediatrics (NYS AAP – Chapter 2)
New York State Chapter 3, American Academy of Pediatrics (NYS AAP – Chapter 3)
Niemann-Pick type C Disease Group
Noah's Hope
NR2F1 Foundation
NTM Info & Research, Inc.
NW Rare Disease Coalition
Ohio Life Sciences Association
Ohio Rare Disease Advisory Council
Organic Acidemia Association
Parents Infant Children of Kernicterus
Pathways for Rare and Orphan Solutions

Patient Advocacy Strategies
Pennsylvania Chapter, American Academy of Pediatrics
Pennsylvania Rare Disease Advisory Council
Pharming Healthcare, Inc.
Phelan-McDermid Syndrome Foundation
Platelet Disorder Support Association
Pompe Alliance
Prader-Willi Syndrome Association | USA
PRISMS
Project Alive
Project GUARDIAN
Pyruvate Kinase Deficiency International Alliance
Quest Diagnostics
Rare Access Action Project
Rare and Black
Raregivers, Inc.
Rare New England
Rare STRIDES
Rare Wish
Revvity
SCAD Alliance
Sickle Cell Association of Kentuckiana
Sickle Cell Disease Association of America, Inc.
Sickle Cell Warriors Foundation, Inc.
SLC6A1 Connect
Smith-Kingsmore Syndrome Foundation
Society for Inherited Metabolic Disorders (SIMD.org)
South Carolina Rare Disease Advisory Council
Speak Foundation
Syngap Research Fund
TANGO2 Research Foundation
Tatton Brown Rahman Syndrome Community
Taylor's Tale
Team Telomere
Team Titin
TED Community Organization
Tennessee Chapter, American Academy of Pediatrics
Terumo Blood and Cell Technologies
The Bonnell Foundation: Living with cystic fibrosis
The Children's Medical Research Foundation, Inc.
The DDX3X Foundation
The Ehlers-Danlos Society
The E.WE Foundation
The Global Foundation for Peroxisomal Disorders

The Lambert-Eaton LEMS Family Association
The Louisa Adelynn Johnson Fund for Complex Disease
The MED13L Foundation
The Oxalosis and Hyperoxaluria Foundation
The Sudden Arrhythmia Death Syndromes (SADS) Foundation
The TBCK Foundation
Tourette Association of America
Travere Therapeutics
TrueNorth
TSC Alliance
Turner Syndrome Society of the United States
UDNF PEER
UH Rainbow Babies & Children's Hospital
United Mitochondrial Disease Foundation
United MSD Foundation
United Pompe Foundation
University of Washington
US Thrombotic Microangiopathy Alliance and Consortium
Usher Syndrome Coalition
Utah Chapter, American Academy of Pediatrics (UTAAP)
Utah Department of Health and Human Services Newborn Screening Program
Utah Rare Disease Advisory Council
Vasculitis Foundation
Virginia Chapter, American Academy of Pediatrics
Virginia Rare Disease Advisory Council
Wadsworth Center, New York State Department of Health
wAIHA Warriors
West Virginia Chapter, American Academy of Pediatrics
Wisconsin Chapter, American Academy of Pediatrics (WIAAP)
Wiskott-Aldrich Foundation
XLH Network, Inc.