Advocacy Organizations for Conditions on the Newborn Bloodspot Screening Panel

Medical Condition	Advocacy Organization
Organic Acid Disorders	
All Organic Acidemias*	Organic Acidemia Assoc
Propionic Acidemia (PA)	Propionic Acidemia Foundation
Fatty Acid Oxidation Disorders	
All Fatty Acid Oxidation Disorders*	Fatty Oxidation Family Support Group
Amino Acid Disorders	
Argininosuccinate lyase deficiency (Argininosuccinic aciduria; ASA)	National Urea Cycle Disorders Foundation
Citrullinemia, type I (CIT)	National Urea Cycle Disorders Foundation
Maple syrup urine disease (MSUD)	MSUD Support Group
Homocystinuria (HCY)	HCU Network
Phenylketonuria (PKU)	National PKU Alliance
Tyrosinemia, type I, II, and III	Tyrosinemia Society Inc
Arginase deficiency (ARG)	Arginase 1 Deficiency Foundation
Endocrine Disorders	
Primary congenital hypothyroidism	American Thyroid Association
Congenital adrenal hyperplasia (CAH)	CAH Foundation, CARES Foundation
Pulmonary Disorders	
Cystic fibrosis (CF)	Cystic Fibrosis Foundation
Other Metabolic Disorders	
Biotinidase deficiency	Biotinidase Support Group
Galactosemia (GALT)	Galactosemia Foundation

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Hemoglobin Disorders	
Sickle cell disease and other hemoglobinopathies	OSWATS, Sickle Cell OR, American Sickle Cell Assoc
Immunology Disorders	
Severe combined immunodeficiency (SCID)	Immune Deficiency Foundation
Lysosomal Storage Disorders	
Pompe (Glycogen storage disease, type II)	Rykers Foundation, Pompe Warrior Foundation
Mucopolysaccharidosis Type I (MPS I)	National MPS Society
Fabry	Family Support Group, National Fabry Disease Foundation
Gaucher	National Gaucher Foundation, Know Gaucher, Gaucher Community Alliance
Infantile Krabbe Disease	KrabbeConnect, Hunters Hope
Other Conditions	
Spinal muscular atrophy (SMA)	Cure SMA Muscular Dystrophy Assoc (MDA)
X-linked adrenoleukodystrophy (X-ALD)	ALD Alliance

*__Organic Acidemias__: Methylmalonic acid(MMA), Isovaleric acidemia (IVA),3-methylcrotonyl CoA carboxylase deficiency (3MCC), 3-hydroxy-3-methylglutaryl CoA lyase deficiency (HMG),
Multiple carboxylase deficiency (MCD), Beta-ketothiolase deficiency (BKT), 2-methyl-3-hydroxybutyryl CoA dehydrogenase deficiency (2M3HBA), Glutaric acidemia, type 1 (GA-1), Malonic acidemia (MAL)
Isobutyrl-CoA dehydrogenase deficiency (IBD), 2-methylbutyryl CoA dehydrogenase deficiency (2MBC), 3-methylglutaconyl CoA hydratase deficiency (3MGH)

***Fatty Acid Oxidation Disorders**: Carnitine uptake deficiency (CUD), Medium chain acyl-CoA dehydrogenase deficiency (MCAD), Very long chain acyl-CoA dehydrogenase deficiency (VLCAD),
Long chain 3 hydroxyacyl-CoA dehydrogenase deficiency (LCHAD)
Trifunctional protein deficiency (TFP), Short chain acyl-CoA dehydrogenase deficiency (SCAD),
Glutaric acidemia type II, also known as Multiple acyl-CoA dehydrogenase deficiency (MADD),
Carnitine palmitoyl transferase deficiency, type I (CPT-I), Carnitine palmitoyl transferase deficiency, type II (CPT-II), Carnitine acylcarnitine translocase deficiency (CACT)

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