REFUSAL FORM - NEWBORN SCREENING

Baby's Name_____ **Date of Birth**_____

Hospital of Birth _____ **Medical Record Number**_____

I understand that:

The State of Maryland and the American Academy of Pediatrics strongly recommend newborn screening. Newborn screening is considered part of good baby care.

Newborn babies are tested for some conditions that cause mental retardation, other serious health problems and even death. Maryland tests babies for all the conditions recommended by the March of Dimes, the American Academy of Pediatrics and the American College of Medical Genetics. Although these disorders are rare, each month several babies are found to have a disorder identified by the newborn screen.

Treatment, if it is started early, can help to prevent the problems caused by these conditions. The State will provide access to complete treatment for every baby found to have a disorder.

Testing all babies is important because babies with these conditions usually look normal.

The tests are done on a small amount of the baby's blood. The blood is collected by pricking the baby's heel.

I understand that if my baby has one of these disorders, and does not have newborn screening, the delay in diagnosis and treatment can result in severe health problems, mental retardation or even death.

I have been provided with information about newborn screening. I know that if I have additional questions I can contact the Newborn Screening Laboratory at the State Health Department at 443-681-3900 or I can go to the State Laboratory's website at http://dhmh.maryland.gov/laboratories (click on Newborn and Childhood Screening).

I have discussed newborn screening with my baby's doctor or nurse,

_____M.D./R.N._____
Doctor's /Nurse's Name Phone Number

My questions have been answered to my satisfaction.

Nevertheless, I do not agree to the collection of a blood sample from my baby for the newborn screening tests.

I accept full responsibility for the decision not to permit my baby to have newborn screening performed.

I release and hold harmless the Maryland Department of Health and Mental Hygiene, the hospital of birth, and the person responsible for collecting the newborn screening sample, for any injury, illness, or medical condition to my child, or even the death of my child, any of which may be caused by a disorder that is screened for under the State's newborn screening comprehensive testing panel, which screening I am hereby refusing for my child.

Parent/Guardian's Name_____ **Signature** _____

Address_____ **Phone Number** _____

Date_____ **Witness**_____ **Signature**_____

Disorders in the Maryland Newborn Screening Panel

(Some disorders have several variants.)

Amino Acid Disorders

Phenylketonuria (PKU) and Hyperphenylalaninemia (Hyperphe)
Homocystinuria (and Hypermethioninemia)
Tyrosinemia I, II, III

Urea Cycle Disorders

Argininosuccinic Aciduria
Argininemia
Citrullinemia I, II

Organic Acid Disorders

BCK (Branched Chain Ketoaciduria) also called MSUD (Maple Syrup Urine Disease)
Biotinidase Deficiency
Glutaric Acidemia, Type I (GA I)
3-Hydroxy-3-Methyl-CoA Lyase Deficiency (HMG CoA Lyase Deficiency)
Isobutyryl-Co-A Dehydrogenase Deficiency (IBC/IBG)
Isovaleric Acidemia (IVA)
Malonic Acidemia (Malonyl-CoA Decarboxylase Deficiency) (MAL)
2-Methylbutyryl-CoA Dehydrogenase Deficiency (2MBG)
3-Methylcrotonyl-CoA Carboxylase Deficiency (3MCC Deficiency)
3-Methylglutaconyl-CoA Hydratase Deficiency (MGA- Methylglutaconyl Aciduria)
2-Methy-3-hydroxy butyric Aciduria (2M3HBA)
Methylmalonic Acidemia (MMA) (MUT, CblA/B, CblC/D)
Mitochondrial Acetoacetyl-CoA Thiolase Deficiency (3-Ketothiolase Deficiency, BKT)
Multiple Carboxylase Deficiency (MCD)
Propionic Acidemia (PA or PPA)

Fatty Acid Oxidation Disorders

Carnitine Uptake Disorder
Carnitine/Acylcarnitine Translocase Deficiency (Translocase Deficiency)
Carnitine Palmitoyl Transferase I Deficiency (CPT I Deficiency)
Carnitine Palmitoyl Transferase II Deficiency (CPT II Deficiency)
Dienoyl-CoA Reductase Deficiency (De-Red Deficiency)
Long Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency (LCHAD Deficiency)
Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD Deficiency)
Medium/ Short Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency (M/SCHAD Deficiency)
Medium Chain Ketoacyl-CoA Thiolase deficiency (MCKAT)
Multiple Acyl-CoA Dehydrogenase Deficiency (MADD or Glutaric Acidemia Type II or GA II)
Short Chain Acyl-Co-A Dehydrogenase Deficiency (SCAD Deficiency)
Trifunctional Protein Deficiency (TFP Deficiency)
Very Long Chain Acyl-CoA Dehydrogenase Deficiency (VLCAD Deficiency)

Endocrine Disorders

Hypothyroidism
Congenital Adrenal Hyperplasia (CAH)

Carbohydrate Metabolism Disorders

Galactosemia (Transferase-GALT, Kinase-GALK, Epimerase-GALE)

Hemoglobin Disorders

Sickle Cell Disease (SCD- including SS, SC, SBeta Thalassemia)

Cystic Fibrosis

Hearing

All babies are screened before hospital discharge