VERMONT
DEPARTMENT OF HEALTH

Agency of Human Services
Division of Maternal and Child Health
Children with Special Health Needs
Vermont Newborn Screening Program

REFUSAL TO CONSENT TO NEWBORN SCREENING

I/We, _____, the parent/guardian(s) of
Name of parent/guardian(s)
_____, born on _____ at
Infant's name Date of birth

_____, refuse to have blood taken from our child for the purpose of
Place of birth
determining if (s)he might have a health condition that can cause death, disability, or illness. The conditions tested for include the thirty-three conditions listed below. It has been explained that the Vermont Department of Health recommends that all babies are tested for these conditions in the newborn period.

3-Methylcrotonyl-CoA carboxylase deficiency (3MCC)
3-OH 3-CH3 glutaric aciduria (HMG)
Argininosuccinic acidemia (ASA)
Beta-ketothiolase deficiency (BKT)
Biotinidase deficiency (BIOT)
Carnitine uptake defect (CUD)
Citrullinemia (CIT)
Congenital adrenal hyperplasia (CAH)
Congenital hypothyroidism (HYPOTH)
Cystic fibrosis (CF)
Galactosemia (GALT)
Glutaric acidemia type I (GA I)
Hb S/Beta-thalassemia (Hb S/Th)
Hb S/C disease (Hb S/C)
Homocystinuria (HCY)
Isovaleric acidemia (IVA)
Long-chain L-3-OH acyl-CoA dehydrogenase deficiency (LCHAD)
Maple syrup urine disease (MSUD)
Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)
Methylmalonic acidemia (Cbl A, B)
Methylmalonic acidemia (MUT)
Mucopolysaccharidosis type I (MPS I)
Multiple carboxylase deficiency (MCD)
Phenylketonuria (PKU)
Pompe disease
Propionic acidemia (PROP)
Severe Combined Immunodeficiency (SCID)
Sickle cell anemia (SCA)
Spinal muscular atrophy (SMA)
Trifunctional protein deficiency (TFP)
Tyrosinemia type I (TYR I)
Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)
X-linked adrenoleukodystrophy (X-ALD)

Other types of screening tests include screening for hearing loss and pulse oximetry to screen for Critical Congenital Heart Disease.

~I/we have been informed that the procedure involves a heel stick to obtain blood for the test.
~I/we have had the opportunity to discuss newborn screening with our baby's doctor, the hospital nursing staff, or other care provider, and all our questions have been answered to our satisfaction.
~I/we further understand that if our baby does have one of these conditions, and the condition is not diagnosed in the newborn period, the risk that our child could have health problems, including intellectual disabilities and/or death, could be very high.
~I/we acknowledge that this form will be filed in our baby's medical record, and copies will be sent to our baby's care provider and the Vermont Department of Health.

_____
Signature of parent/guardian(s) date

_____
Signature of witness date

Instructions:

1. This form must be completed for all infants when the parent/guardian(s) decline newborn screening. The original signed copy must be filed in the infant's medical records or in the case of home births, in the record kept by the birth attendant.
2. Photocopies should be sent to the infant's primary care provider and to the Vermont Newborn Screening Program at P.O. Box 70, 108 Cherry St., Burlington, VT 05402. Please call (802) 951-5180 with questions.