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 REPEAT 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. We understand that the initial specimen obtained was unsatisfactory for testing or indicated a need to repeat the screening. The conditions tested for include the thirty-three conditions listed below. I/we understand 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 which can be done in the home or hospital include screening for hearing loss and pulse oximetry to screen for Critical Congenital Heart Disease.

~I/we have read the brochure provided by the Vermont Department of Health Newborn Screening Program and understand that the Health Department recommends that all babies are tested for these conditions in the newborn period.
~I/we understand that the Vermont Newborn Screening Program recommends that follow-up testing be done because the test done on _____ showed a result that is concerning for _____.
~I/we feel that we have all the information necessary and have made the decision not to have newborn screening repeated for our baby/babies.
~I/we do not wish to discuss newborn screening further with newborn screening staff, our baby's doctor, or other care providers who are available to answer related questions.
~I/we understand that if our baby does have one of these conditions and it 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.

_____
Signature of parent/guardian(s) date

_____
Signature of witness date

Please mail this form to the Vermont Newborn Screening Program, PO Box 70, 108 Cherry St., Burlington, VT 05402. Please call (802) 951-5180 with questions.