

**NEWBORN BLOOD SPOT SCREENING
LABORATORY**

BC Children's Hospital
4480 Oak Street, Room 2F27
Vancouver, BC V6H3V4
Ph: (604) 875-2148
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Place Infant's
Addressograph/Label Here

INFORMED REFUSAL: NEWBORN BLOOD SPOT SCREENING

I refuse to consent to my baby receiving the newborn blood spot screening tests listed below.

I choose this knowing that:

- Newborn screening is considered standard of care for all newborns born in BC and the Yukon.
- Testing for more than 25 treatable conditions is done by taking a few drops of blood from my baby's heel.
- One in 750 babies are born with one of these treatable conditions.
- Babies with these conditions, when found and treated early, have significantly improved health outcomes.
- My baby may look healthy now but could still have one of these treatable conditions.
- If my baby has one of these conditions, and is not screened and treated early, my baby could have serious developmental delay and other health problems, or may even die.

Name of Parent / Legal Guardian First and Last name (please print clearly)

Signature

Date

Witness (patient's most responsible health care provider). I watched the parent / guardian sign the refusal form.

Witness First and Last Name (please print)

Witness Signature

Date

The treatable conditions in British Columbia's Newborn Blood Spot Screening Program:

Metabolic Disorders

Amino Acid Disorders:

- Phenylketonuria (PKU)
- Maple Syrup Urine Disease (MSUD)
- Citrullinemia (CIT)
- Argininosuccinic Acidemia (ASA)
- Homocystinuria (Hcy)
- Tyrosinemia I (Tyr I)
- Guanidinoacetate Methyltransferase Deficiency (GAMT)

Fatty Acid Oxidation Disorders:

- Medium-chain Acyl-CoA Dehydrogenase Deficiency (MCAD)
- Long-chain Hydroxyacyl-CoA Dehydrogenase Deficiency (LCHAD)
- Very-long chain AcylCoA Dehydrogenase Deficiency (VLCAD)
- Carnitine Uptake Disorder (CUD)

Organic Acid Disorders:

- Propionic Acidemia (PROP)
- Methylmalonic Acidemia (MUT) and B12 Deficiency
- Cobalamin Disorders (Cbl A,B)
- Glutaric Aciduria Type 1 (GA I)
- Isovaleric Acidemia (IVA)
- Biotinidase Deficiency

*Galactosemia
(GALT)*

Endocrine Disorders

- Congenital Hypothyroidism (CH)
- Congenital Adrenal Hyperplasia (CAH)

**Sickle Cell Disease and other
Hemoglobin Disorders**

Cystic Fibrosis (CF)

Spinal Muscular Atrophy (SMA)

**Severe Combined
Immunodeficiency
(SCID)**

For health care provider use ONLY: see link for more information: <http://www.perinatalservicesbc.ca/health-professionals/professional-resources/screening/newborn>

- ☐ Fax this refusal form to NBS program 604-875-3836
- ☐ Place copy of this signed form in baby's health record
- ☐ Notify the infant's physician or midwife of the refusal