

Last Name <i>(Legal)</i>		First Name <i>(Legal)</i>	
Preferred Name <input type="checkbox"/> Last <input type="checkbox"/> First		DOB <i>(dd-Mon-yyyy)</i>	
PHN	ULI <input type="checkbox"/> Same as PHN	MRN	
Administrative Gender <input type="checkbox"/> Male <input type="checkbox"/> Female		<input type="checkbox"/> Non-binary/Prefer not to disclose (X)	

Refusal for Newborn Blood Spot Screen

I refuse to give informed consent for my baby to have a newborn blood spot screen within the Alberta Newborn Screening Program.

I choose to refuse newborn blood spot screening knowing that

- A few drops of blood are needed from a baby's heel to screen for 22 treatable conditions listed below, and
- A baby may look and act healthy, but could still have one of the 22 treatable conditions, and
- If a baby has one of the 22 treatable conditions, and is not screened, he or she could have health problems or may even die.

By signing this refusal, I confirm that

- I understand the information I have been given about the newborn blood spot screen and the Alberta Newborn Screening Program, and
- I have had an opportunity to discuss my questions and concerns about the newborn blood spot screen and the Alberta Newborn Screening Program with my health care professional and my questions have been answered, and
- I am making this decision freely, and
- I have the legal authority to refuse the newborn blood spot screen.

Name of parent/guardian with legal authority *(Last, First)*

Signature of parent/guardian with legal authority

Date *(dd-Mon-yyyy)*

Witness *(Witness[es] must be a health care provider at least 18 years of age)*

- I watched the parent/guardian sign the refusal form *(the patient's most responsible health practitioner)*
- We listened to the phone call where the parent/guardian verbally refused *(two health care provider witnesses required, one being the patient's most responsible health practitioner)*

Witness #1 *(Last, First Name)*

Witness Signature

Date *(dd-Mon-yyyy)*

Witness #2 *(Last, First Name)*

Witness Signature

Date *(dd-Mon-yyyy)*

The Treatable Conditions in the Alberta Newborn Screening Program

Metabolic conditions: Biotinidase deficiency (*BIOT*); Carnitine uptake defect (*CUD*); Citrullinemia (*CIT*); Glutaric acidemia type 1 (*GA1*); Classic galactosemia (*GALT*); 3-Hydroxy-3-methylglutaryl-CoA lyase deficiency (*HMG*); Isovaleric acidemia (*IVA*); Long chain 3-hydroxyacyl-CoA dehydrogenase deficiency (*LCHAD*); Medium chain acyl-CoA dehydrogenase deficiency (*MCAD*); Methylmalonic acidemia (*MMA*); Maple syrup urine disease (*MSUD*); Propionic acidemia (*PA*); Phenylketonuria (*PKU*); Tri-functional protein deficiency (*TFP*); Tyrosinemia Type 1 (*TYR1*); Very long chain acyl-CoA dehydrogenase deficiency (*VLCAD*)

Endocrine Conditions: Congenital adrenal hyperplasia (*CAH*); Congenital hypothyroidism (*CH*)

Cystic Fibrosis (*CF*), Severe Combined Immunodeficiency (*SCID*), Sickle Cell Disease (*SCD*), Spinal Muscular Atrophy (*SMA*)

For Health Care Professional use ONLY See <http://www.ahs.ca/newbornscreening> for more information

- Mark the blood spot card as PARENT REFUSAL, complete infant demographics and send blood spot card to Alberta Newborn Screening Laboratory, U of A Hospital
- Notify the infant's physician or midwife of the refusal
- Include refusal form and document refusal in the infant's health record located at _____
- Fax refusal form to Alberta Newborn Screening Program: 403.476.8782