#### **NEWBORNS: TESTING AND REPORTING**

### Are screening tests for newborns required?

Yes. Except where a newborn's parent or guardian objects on religious grounds, screening tests of all newborn infants before discharge from the hospital are required for the detection of phenylketonuria and other heritable or metabolic disorders leading to intellectual disabilities or physical defects.<sup>1</sup>

The hospital performing the birth services must provide information to the parents or responsible parties regarding:<sup>2</sup>

- The purpose of screening newborns for congenital disorders.
- The list of disorders for which screening is performed.
- The requirement for newborn screening.
- The parent's legal right to refuse testing because of religious tenets or practices.
- The specimen storage, retention and access procedures required by the State.

The information above may be provided by a pamphlet from the Department of Health, or by other means.

A blood specimen must be obtained from each newborn prior to discharge from the hospital, or if not yet discharged, no later than five days after birth.<sup>3</sup> If a parent or guardian refuses to allow newborn metabolic screening, the parent or guardian's signature must be obtained on a refusal form specified by the Department of Health.<sup>4</sup> The specimen or signed refusal must be forwarded to the state public health laboratory no later than one day after the specimen is collected or the refusal form is signed.<sup>5</sup>

Upon receipt of the specimen, the state public health laboratory will perform screening tests for the following:<sup>6</sup>

- Biotinidase deficiency.
- Congenital hypothyroidism.

<sup>2</sup> WAC 246-650-020(1)(a).

<sup>&</sup>lt;sup>1</sup> RCW 70.83.020.

<sup>&</sup>lt;sup>3</sup> WAC 246-650-020(1)(b).

<sup>&</sup>lt;sup>4</sup> WAC 246-650-020(1)(e).

<sup>&</sup>lt;sup>5</sup> WAC 246-650-020(1)(f).

<sup>&</sup>lt;sup>6</sup> WAC 246-650-020(2)(a).

- Congenital adrenal hyperplasia.
- Galactosemia.
- Homocystinuria.
- Hemoglobinopathies.
- Maple syrup urine disease.
- Medium chain acyl-coA dehydrogenase deficiency.
- Phenylketonuria.
- Cystic fibrosis.
- The amino acid disorders: Argininosuccinic acidemia (ASA), citrullinemia (CIT), and tyrosinemia type I (TYR 1).
- The fatty acid oxidation disorders: Carnitine uptake defect (CUD), long-chain L-3-OH acyl-CoA dehydrogenase deficiency (LCHADD), trifunctional protein deficiency (TFP), and very long-chain acyl-CoA dehydrogenase deficiency (VLCADD).
- The organic acid disorders: 3-OH 3-CH3 glutaric aciduria (HMG), beta-ketothiolase deficiency (BKT), glutaric acidemia type I (GA 1), isovaleric acidemia (IVA), methylmalonic acidemia (CblA,B), methylmalonic acidemia (*mutase deficiency*) (MUT), multiple carboxylase deficiency (MCD), propionic acidemia (PROP).

The laboratory will report significant test results to the newborn's attending physician or the newborn's family if the attending physician cannot be identified.<sup>7</sup> The Department of Health will offer the diagnostic and treatment resources of the department to physicians attending affected infants.<sup>8</sup>

# May screening tests be given to a newborn whose parent or guardian objects on religious grounds?

No. No screening tests may be given to any newborn whose parent or guardian objects on religious grounds.<sup>9</sup>

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<sup>&</sup>lt;sup>7</sup> WAC 246-650-020(2)(b).

<sup>&</sup>lt;sup>8</sup> WAC 246-650-020(2)(c).

<sup>&</sup>lt;sup>9</sup> RCW 70.83.020.

## When may a newborn be tested for AIDS/HIV?

Testing for AIDS/HIV may be performed on newborn infants with the consent of the newborn's parent or legal representative. <sup>10</sup> <u>See AIDS/HIV/STD.</u>

## Must phenylketonuria testing results be reported?

Laboratories, attending physicians, hospital administrators, or other persons performing or requesting any test for phenylketonuria must report all positive results to the Department of Health. 11

<sup>&</sup>lt;sup>10</sup> RCW 7.70.065(1). <sup>11</sup> RCW 70.83.030.