OREGON HEALTH AUTHORITY

September 24, 2024

Newborn Bloodspot Screening Program

Presented to House Behavioral Health and Health Care Committee

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What is Newborn Bloodspot Screening?

Newborn screening is a **state public health program** that identifies infants with **treatable** disorders, which may otherwise go **unrecognized**, to avoid or prevent **adverse outcomes, including death.**

Baby Maisie

Newborn Bloodspot Screening Program

Pre-analytic

Analytic

Post-analytic

Education
Parents
Providers
Public

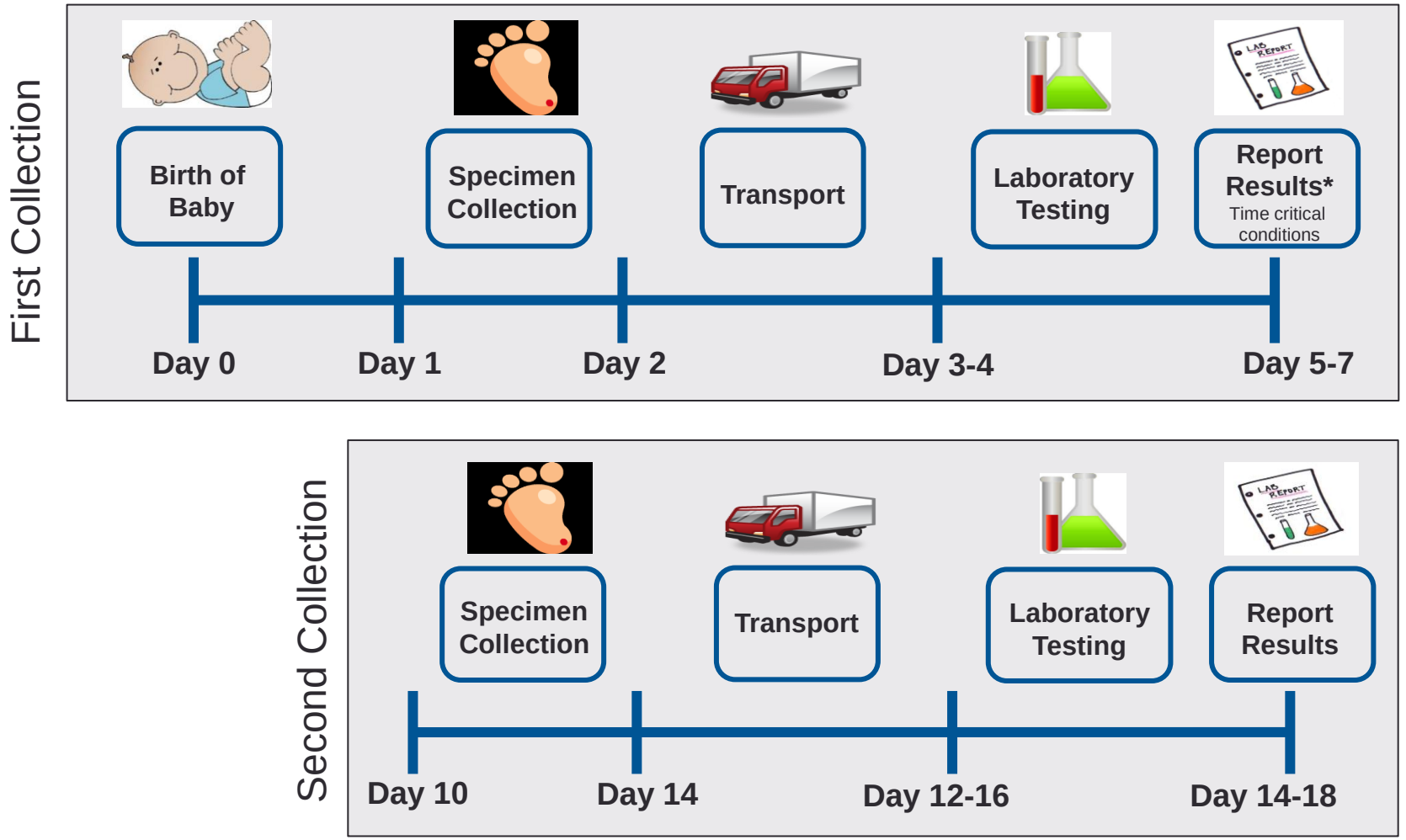
Specimen Collection

Transport

Laboratory Testing

Follow-up

Newborn Bloodspot Screening Timeline



History of Conditions Added to the Oregon Newborn Screening Panel

1963	**Oregon starts screening program for Phenylketonuria, one of the first in nation**
1975	Screening for Congenital Hypothyroidism
1985	Screening for Biotinidase Deficiency
1995	Screening for Hemoglobinopathies
2002	Screening for amino acid disorders, organic acidemias, fatty acid oxidation defects
2003	Screening for Congenital Adrenal Hyperplasia
2006	Screening for Cystic Fibrosis
2014	Screening for SCID
2018	Screening for Pompe, MPSI, Gaucher, Fabry
2022	Screening for SMA
2023	Screening for XALD

Presently, Oregon Screens for 45 conditions that require immediate treatment to prevent adverse outcomes.

Cornerstones of the NBS Program

- **Access to screening**
  - Matching of NBS record to vital statistics/birth record Ensure all newborns have access to screening regardless of parents/guardian's ability to pay
- **Timeliness of screening**
  - Provide courier service to rural/frontier hospitals to ensure the timely delivery of samples to the laboratory
- **Education and outreach to public, providers, & parents**
  - NBS brochure in 11 languages and website enhancements
- **Access to clinical care and treatment**
  - Partner with OHSU and CCO to assist families whose child has screened positive for a condition
- **Expansions of NBS panel of conditions**
  - Advisory board criteria for condition review to include family and advocacy groups

Advisory Board & Screening Panel

2019	Representative McLain sponsored legislation to form the advisory board
2022	Screening for Spinal Muscular Atrophy (SMA) was implemented at the recommendation of the advisory board
2023	Screening for X-linked Adrenal Leukodystrophy (XALD) was implemented at the recommendation of the advisory board
	One time general funds were provided to start-up SMA
	Fee increase was ratified in 2022, covered ongoing screening for SMA and XALD
	Advisory board recommended addition of Mucopolysaccharidosis Type II
	Advisory board recommended addition of GAMT deficiency
	At this time, there is no date set for implementation of these two new conditions
2024	Advisory board will review Krabbe disease in December for inclusion on the panel
	Request for the advisory board to consider Duchenne Muscular Dystrophy
	Request for the advisory board to consider cytomegalovirus (CMV) screening

Thank you

You can get this document in other languages, large print, braille or a format you prefer free of charge. Contact Patrice Held at Patrice.k.Held@oha.oregon.gov or 503-693-4172 (voice/text). We accept all relay calls.

Public Health Division
Newborn Screening Program
Oregon State Public Health Laboratory
https://www.oregon.gov/oha/ph/laboratoryservices/newbornscreening/pages/index.aspx

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