

Washington State Newborn Screening Program

Timeliness of Parent Notification by Health Care Providers

Births January 1, 2017 - December 31, 2017

When screening results indicate an infant requires diagnostic testing and evaluation, the Newborn Screening Program contacts the infant's health care provider with disorder-specific recommendations. The provider is then responsible for informing the parents. Health care providers are required to notify the Newborn Screening Program of the date they communicated the need for diagnostic testing to the parent or guardian ([70.83.070 RCW](#)). Referrals are classified into two types:

Standard Referrals

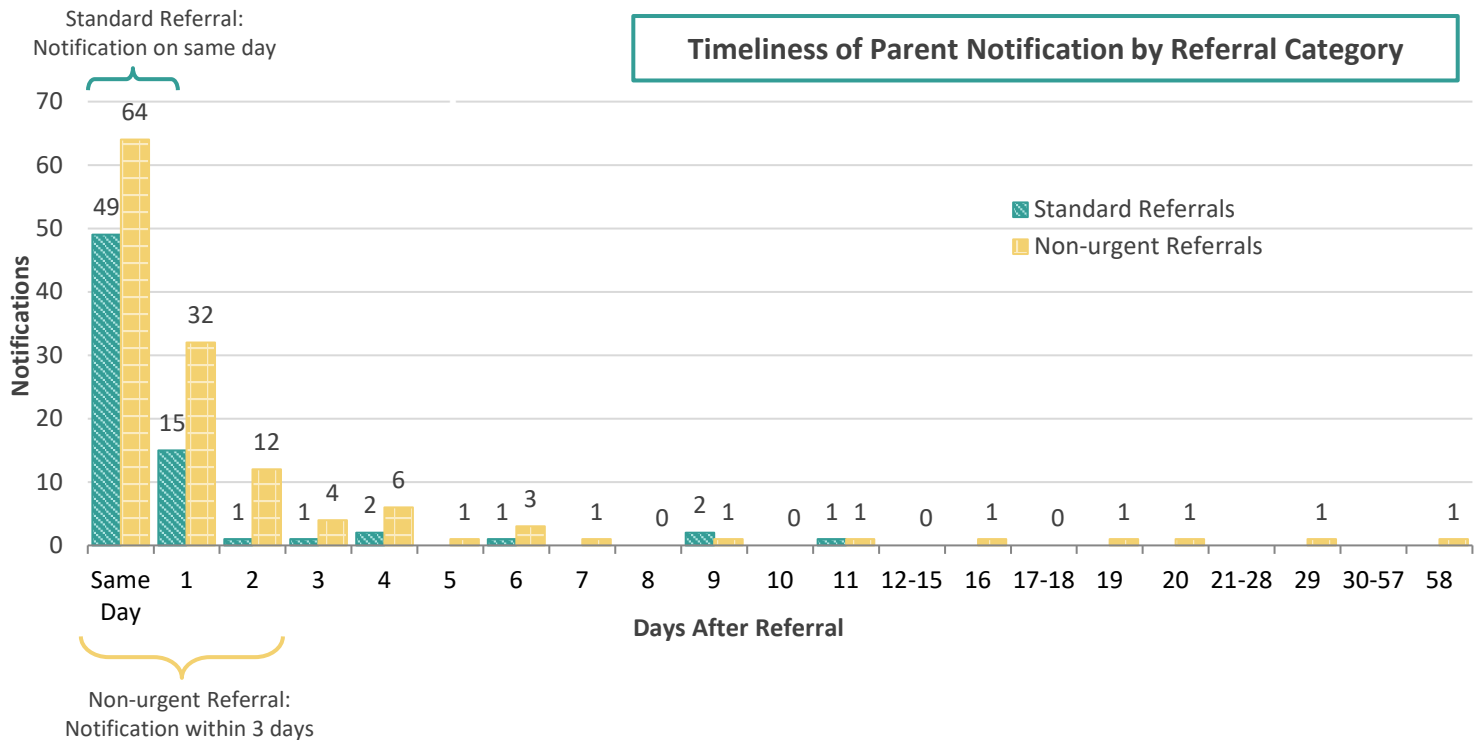
Due to the potential severity of the condition clinical evaluation and diagnostic testing should be done immediately. Parents should be notified the same day as the referral.

Non-urgent Referrals

Diagnostic testing and evaluation should be done as soon as possible. Parents should also be notified as soon as possible, ideally within three days of the referral.

Newborn Screening Referral Category	Infants Referred for Diagnostic Testing		Health Care Provider Reported Date of Parent Notification		On-time Parent Notification	
	Total	Percent	Total	Percent	Total	Percent
Standard Referral	141	39.9%	72	51.1%	49	68.1%
Non-urgent Referral	212	60.1%	130	61.3%	108	83.1%
All Referrals	353*	100%	202	57.2%	157	77.7%

*Excludes 27 instances where the health care provider began diagnostic testing prior to screening results based on family history, prenatal diagnosis, or clinical symptoms.

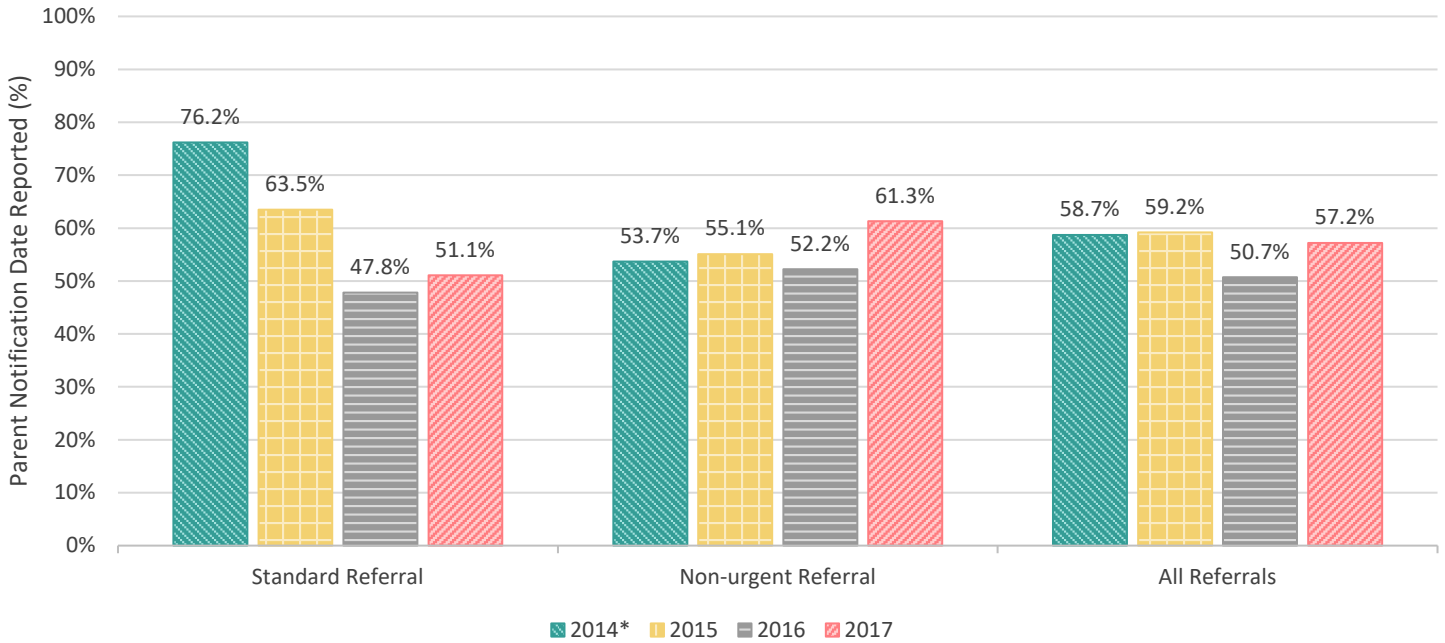


Disorders included in Standard Referrals: Congenital adrenal hyperplasia (CAH), Congenital hypothyroidism (CH), Cystic Fibrosis (CF), Glutaric acidemia type I (GA-I), Galactosemia (GALT), Isovaleric acidemia (IVA), Maple syrup urine disease (MSUD), Medium chain acyl-CoA dehydrogenase (MCAD) deficiency, Methylmalonic acidemias (MMA)/Propionic acidemia, Phenylketonuria (PKU), Severe combined immunodeficiency (SCID), and Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency.

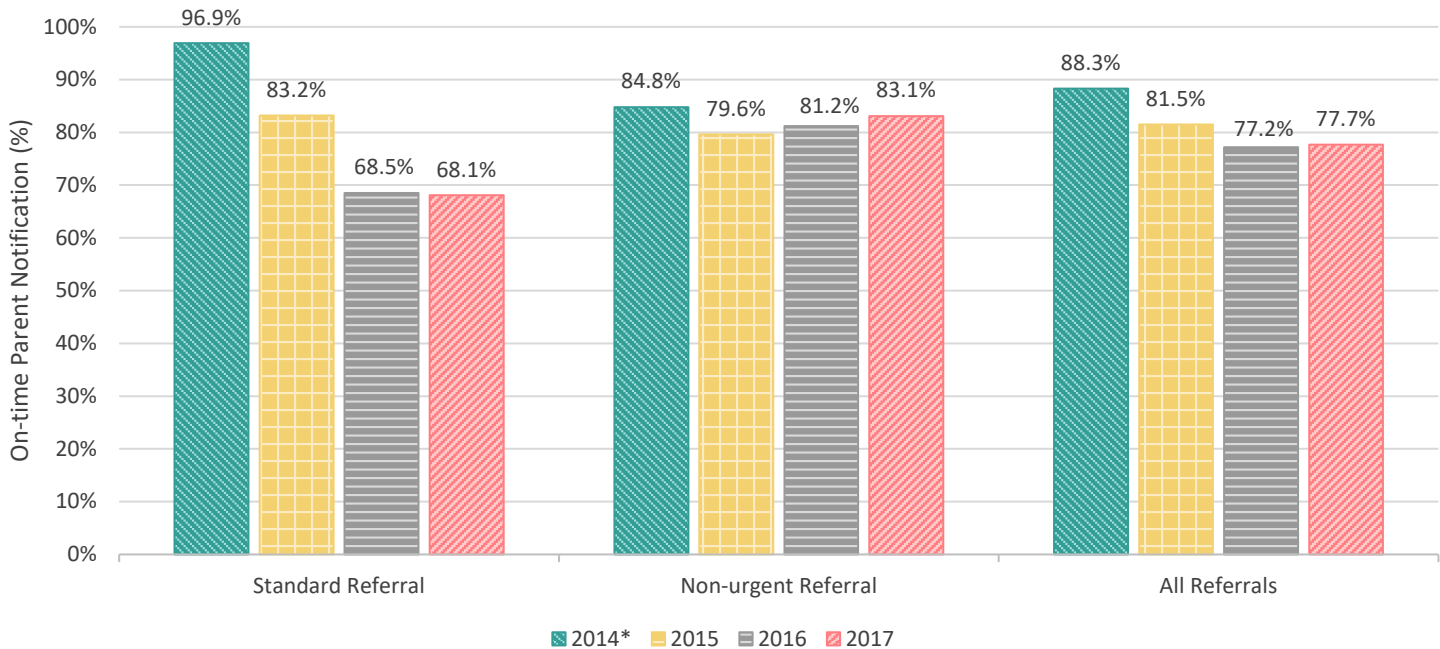
Disorders included in Non-urgent Referrals: Congenital adrenal hyperplasia (CAH), Cystic fibrosis (CF), Mild congenital hypothyroidism (CH), Carnitine uptake defect (CUD), Homocystinuria (HCY), Hemoglobinopathies (HB), 3-hydroxy-3-methylglutaric aciduria (HMG)/ Multiple carboxylase deficiency (MCD), Isovaleric acidemia (IVA), Methylmalonic acidemias (MMA)/Propionic acidemia, and Severe combined immunodeficiency (SCID).

Washington State Newborn Screening Program Annual Parent Notification Measures Received July 1, 2014 - December 31, 2017

Annual Parent Notification Reported - Referral Category¹



Annual On-time Parent Notification - Referral Category¹



*Includes data from July 1, 2014- December 31, 2014.

¹ **Standard Referrals:** Due to the potential severity of the condition clinical evaluation and diagnostic testing should be done immediately. Parents should be notified the same day as the referral. **Non-urgent Referrals:** Diagnostic testing and evaluation should be done as soon as possible, ideally within three days of the referral.