PER FOR MANCE NOTE: AGENCY FORM SHORT TITLE: Newborn Screening for Critical Congential Heat  Joint Rule 4-2-404 requires a Performance Review Note anytime the legislature significantly increases funding for:  New agency x New services or benefits  Serving a new or larger population  DUE TO THE FISCAL ANALYST: Russell Frandsen, ASAP  CONTACT INFORMATION RESPONDENT: Richard Harward  Title: Bureau Director, Children Special Health Care Needs Agency: UDOH DFHP  Cell:  Office: 801 584 8529  e-mail: rharward@utah.gov						
HOW WILL THE PUBLIC BENEFIT?						
1 What is the purpose and the duties of the new program, agency, services, or population served? JR4-2-404(4)(c)(i)						
The purpose is to screen all newborns for critical congenital heart defects (CCHD) that can be fatal if not identified early. The screening process will be conducted by the birth facilities. The UDOH will be involved in training birth facilities, educating parents as indicated by the new legislation.						
2 What services are provided by the funding increase? JR4-2-404(4)(c)(ii)						
UDOH personnel to develop training materials for birthing facilities and educational materials for families.						
3 What are the expected outcomes of the new or expanded program and how will the public benefit? JR4-2-404(4)(c)(iii)						
The incidence of CCHD is approximately 1/1,000. CCHD accounts for nearly 30% of infant deaths due to birth defects. Less than 40% of major heart defects are identified prenatally. It is estimated that .6/1000 births will be identified with a non-prenatally diagnosed CCHD and directly benefit. Estimating ~ 53,000 Utah births per year, ~32 newborns in Utah/year will be identified. Identifying these newborns before they are discharged to home will save their lives or reduce their morbidity/complications of future interventions/surgery resulting in lower costs.						
4 How will the bill be implemented and what resources are available to achieve the expected outcomes? JR4-2-404(4)(c)(iv)						
Prior to implementation, two pilot studies, funded through a federal grant, will be conducted to develop appropriate protocols and screening values for Utah's high elevation. Statewide implementation will begin October, 2014. Utah currently has a newborn screening program, and a birth defects surveillance program that will be involved with setting up this new program.						
5 How will the proposed agency activities cause the expected outcomes and public benefit in 3?						
The Newborn Screening Program will develop educational and training materials for birthing facilities in Utah.						

What measures will managers and policymakers use to know if the new or expanded program is providing the expected outcomes and public benefits? Provide one, two, and three year goals or targets, actual results and measures if available							
to serve as a baseline, and outcomes.							
Goal (public benefit	th): All neborns born in birthing facil	lities will b	e screened	1 for CCH	D		
Measure Title:							
Description:	Beginning in October 2014 (SFY 2015) all birthing facilities will provide CCHD screening to newborns after 24 hours of age using the recommended screening protocol for Utah. Birthing facilities will be expected to implement and monitor their screening process						
Fiscal Yea	ar:	FY 2013	FY 2014	FY 2015	FY 2016	FY 2017	
Target or Benchmar	rk:						
Baselin	ne:						
How will progra	am managers collect this performanc	e informa	tion and o	ensure its	reliability	?	
Goal (public benefit	t):						
Measure Title:							
Description:		FV 2012	FV 2014	FV 2015	FY 2016	EV 2017	
Fiscal Yea Target or Benchmar		FY 2013	FY 2014	FY 2015	F1 2010	FY 2017	
Baselin							
					ļ		
How will progra	am managers collect this performanc	e informa	ition and o	ensure its	reliability		
Goal (public benefit	t):						
Measure Title: Description:							
Fiscal Yea		FY 2013	FY 2014	FY 2015	FY 2016	FY 2017	
Target or Benchmar							
Baselin	ne:						
How will progra	am managers collect this performanc	e informa	tion and e	ensure its	reliability		

2. PERFORMANCE MEASURES: