# Critical Congenital Heart Disease Screening and Reporting



Missouri Department of Health and Senior Services
November 9, 2017

### CHD vs. CCHD

#### Congenital Heart Defects (CHD):

- Present at birth and can affect the structure of a baby's heart and the way it works, varying from mild to severe.
- Affect approximately 1% of, or about 40,000, births per year in the United States.
- Most common type of birth defect.
- Leading cause of birth defectassociated infant illness and death.

### Critical Congenital Heart Defects (CCHD):

- Specific CHDs which require surgery or catheter intervention within the first year of life.
- About I in every 4 babies born with a heart defect has a CCHD.
- Typically lead to low levels of oxygen in the newborn and may be identified by pulse oximetry at 24 hours of age.

### Screening Background/Timeline

 AHA/AAP Statement 2009 SACHDNC recommended adding CCHD Screening to the RUSP 2010 Work group publication, guidelines endorsed by AAP, AHA, ACCF Endorsement from HHS Secretary to add CCHD screening to the RUSP 2011 Survey of Missouri hospitals 2012 Missouri Legislation passed - "Chloe's Law" 2013 • CCHD screening required for all babies in Missouri 2014

### Chloe's Law

- 191.334 Revised Statutes of Missouri
  - Every newborn born in Missouri must be screened for CCHD beginning January 1, 2014.
  - Screening shall be done by pulse ox or in another manner as directed by the department in accordance with AAP and AHA guidelines.
  - Results shall be reported to the parents or guardians and to the department in a manner prescribed by the department for surveillance purposes.
  - Facilities/Individuals shall develop and implement plans to ensure that newborns with a positive screen receive appropriate confirmatory procedures and referral for treatment as indicated.

# Voluntary Aggregate Reporting



Ambulatory Surgical Center/Birth Hospital/Birthing Center/Midwife:



#### Critical Congenital Heart Disease Aggregate Reporting Form

The Department of Health and Senior Services requests that all ambulatory surgical centers, hospitals, birthing centers, and midwives who attend home births voluntarily provide aggregate Critical Congenital Heart Disease (CCHD) screening data monthly. Please complete the form below and mail to the Department of Health and Senior Services, Bureau of Genetics and Healthy Childhood, PO Box 570, Jefferson City, MO 65102 or fax to 573-751-6185.

For questions or concerns, please contact the Bureau of Genetics and Healthy Childhood at 573-751-6266.

· <del></del>	
Contact Name:	
Contact Phone Number:	
Reporting Period for Month of:	
Total Number of Newborns Screened	I
Total Number of Newborns with a Negative Screen (Pass)	
Total Number of Newborns with a Positive Screen(Fail/Refer)	
Total Number of Newborns Not Screened Due to:	
Prenatal CCHD diagnosis	
Condition Unstable/Required Critical Intervention	
Parents Refused	
Transferred	
Expired	

#### www.health.mo.gov

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The Missouri Department of Health and Senior Services will be the leader in promoting, protecting and partnering for health.

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(10/13)

- Number of Newborns Screened
- Number with a Negative Screen (Pass)
- Number with a Positive Screen (Fail)
- Number Not Screened
  - Prenatal CCHD diagnosis
  - Condition Unstable
  - Parents Refused
  - Transferred
  - Expired

### 19 CSR 40-12.010

- Final rules for CCHD screening have been filed with the Secretary of State.
- Will become effective November 30, 2017.
- Rules establish screening guidelines and provide direction for the reporting of screening results.
- Requires screening to be done by pulse ox in accordance with AAP and AHA guidelines.
- Requires all screening results and refusals to be reported utilizing either the Missouri Electronic Vital Records (MoEVR) system or paper form.
- Screening results must be reported within 30 calendar days of completion of CCHD screening.

- Recommended guidelines endorsed by the AAP and AHA.
  - Kemper, A., et al. (2011). Strategies for implementing screening for critical congenital heart disease. Pediatrics, vol 128 no. 5, pp e1259-e1267.
    - Article can be found at <u>www.health.mo.gov/cchd</u>

#### Measurement #1

Pulse Ox on Right Hand (RH) and One Foot After 24 hours of Age

#### **FAIL**

Pulse ox of 89% or less in either the RH or foot.

Action: Do Not Repeat Screening,
Refer for Immediate
Assessment.

#### **RETEST**

Pulse ox of 90-94% in both the RH and foot OR a difference of 4% or more between the RH and foot. Action:

Repeat pulse ox in I hour.

#### **PASS**

Pulse ox of 95% or more in the RH or foot AND difference of 3% or less between the two. Action: Do Not Repeat Screening, Provide Normal Newborn Care.

#### Measurement #2

Pulse Ox on Right Hand (RH) and One Foot I Hour After Measurement #I

#### **FAIL**

Pulse ox of 89% or less in either the RH or foot.

Action: Do Not Repeat Screening,
Refer for Immediate
Assessment.

#### **RETEST**

Pulse ox of 90-94% in both the RH and foot OR a difference of 4% or more between the RH and foot. Action:

Repeat pulse ox in I hour.

#### **PASS**

Pulse ox of 95% or more in the RH or foot AND difference of 3% or less between the two. Action: Do Not Repeat Screening, Provide Normal Newborn Care.

#### Measurement #3

Pulse Ox on Right Hand (RH) and One Foot I Hour After Measurement #2

#### **FAIL**

Pulse ox of 89% or less in either the RH or foot.

Action: Do Not Repeat Screening, Refer for Immediate

Assessment.

#### **RETEST**

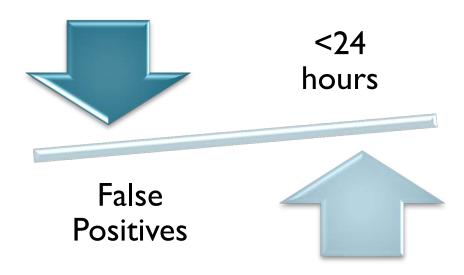
Pulse ox of 90-94% in both the RH and foot OR a difference of 4% or more between the RH and foot. Action: Do Not Repeat, Refer for Clinical Assessment.

#### **PASS**

Pulse ox of 95% or more in the RH or foot AND difference of 3% or less between the two. Action: Do Not Repeat Screening, Provide Normal Newborn Care.

# Age at Screening

- CCHD screening should be performed at 24 to 48 hours of age.
  - False positives are significantly higher when screening is done prior to 24 hours of age.



### Screening Sites

Screening should be performed on the right hand (preductal) AND either foot (post-ductal)







RH application site

Foot application site



The Missouri Electronic Vital Records (MoEVR) system is an online data entry system used to support the registration of Missouri vital events for the DHSS and other users such as birthing facilities, attending physicians, funeral directors, and medical examiners.

Save

Print

Reset

MISSOURI DEPARTMENT OF HEALTH AND SENIOR SERVICES BUREAU OF VITAL RECORDS VITAL RECORDS USER ACCESS REQUEST P.O. BOX 570 JEFFERSON CITY, MO 65102-0570 TELEPHONE (573) 526-0348 FAX (573) 526-3846

	Send completed form to Bureau of Vital Records at the address above. (Attach separate sheet if necessary). PLEASE PRINT.									
IDENTIFYING INFORMATION										
NAME (LAST, FIRST, MI)  OFFICE ADDRESS (STREET, CITY, ZIP)					ACTION REQUESTED  ADD USER  ADD ACCESS	E-MAIL FAX				
	SOCIAL SECURITY NUMBER (LAST 4 DIGITS ONLY	COUNTY (FOR MEDIC	DELETE USER DELETE ACCESS	☐ TELEPHON	NE					
	E-MAIL ADDRESS		☐ TRANSFER ☐ NAME CHANGE							
					FORMER NAME	_				
	OFFICE TELEPHONE	OFFICE FAX								
1	SELECT ROLE(S) THAT APPLY:									
	DATA ENTRY: This role will allow data allow data to allow									
4	BIRTH	DEATH		DEAT	н	FETAL DEAT	н			
	☐ Data Entry Clerk-Facility	☐ Funeral Direct	or		ata Entry Clerk-Physician	Person En				
	Data Entry Clerk-Hearing Screening	Data Entry Cle	erk-Funeral Home	_	ta Entry Clerk-Physician Assist					
	☐ Data Entry Clerk-CCHD	Data Entry Cle			ta Entry Clerk-Assistant Physic					
		Medical Exam	iner/Coroner	∐ Da	ta Entry Clerk-Advanced Practi	ce Registered Nurse				
1	CERTIFIER/DE-CERTIFIER: This role w									
	to pending certification queues and may Senior Services, Bureau of Vital Records		birth records, deat	h records	and/or fetal death records to th	e Missouri Departme	ent of Health and			
	BIRTH	DEATH		DEAT	u	EMBALMER				
	Facility Certifier/Midwife	Physician (MD	)/DO)	Physician Assistant Embalm						
	Physician (MD/DO)	Medical Exam	- /	Assistant Physician						
				☐ Ac	Ivanced Practice Registered Nu	irse				
LICENSED FUNERAL DIRECTOR LICENSE NUMBER  LICENSED CERTIFIER					Fadility: List name and complete address of each facility associated for this use: Funeral homes: include funeral establishment leones number for each builty. Data Entry Clerk or Person authorized to enter medical information: List name and iconse number for each physician/medical centre resociated with this user. Patch additional page(s) if necessary.					
MD Physician Assistant Assistant Physician					scarmoca order ascard war as	user. Atachi additional page	a) i nocusary.			
	☐ DO ☐ Advanced Practice Reg	istered Nurse		1)						
	LICENSE NUMBER	NPI		2)						
LICENSED EMBALMER These roles are for the purpose of complying with embalming requirements.				3)						
	Licensed Embalmer			4)						
	Student Embalmer			5)						
Failure to comply with embalming requirements constitutes grounds for revocation of license.				6)						
COMMENT										
SECURITY STATEMENT/APPROVALS										
	I, the undersigned, an employee of the facility listed above and user of the Missouri Department of Health and Senior Services, Vital Records McEVR Web system, understand that approval and assignment of the requested to or approval of the requested change enables me to access the resources which, by law, must be utilized only in the performance of my assigned duties. Therefore, I agree to make no iniquities or updates which are not required in the performance of my official duties. I understand that state and tederal statutes require confidentiality of information and provide penalties for unauthorized access, use and/or disclosure of information. Volations or disclosures on my part may result in disciplinary action that could be one or at of the following; (1) suspension or demission from the system or (2) civil count action. I agree to keep confidential all information made available to me in the performance of my official duties. In addition, I agree not to divulge or share my password with anyone.									
	USER SIGNATURE		DATE	SUPERVIS	DR/SUPERVISING PHYSICIAN SIGNATU	RE	DATE			
	DEDARTMENT LICE ONLY									
	DEPARTMENT USE ONLY									
	DIVISION/PROGRAM SIGNATURE		DATE	DIMSIONP	ROGRAM SIGNATURE		DATE			

- To access the MoEVR
   website, the application
   form, Vital Records User
   Access Request, must be
   completed by the applicant
   and approved by the
   Bureau of Vital Records.
- To obtain this form, you will need to contact the Bureau of Vital Records either by
   phone at 573-526-0348 or
  - email at <a href="moevrsupport@health.mo.gov">moevrsupport@health.mo.gov</a>.
- Vital Records will not process requests for access to CCHD data entry until November 30th.

### Logging into MoEVR

The web address to log into MoEVR is:

https://moevr.dhss.mo.gov/moevr/gui/login/welcomeMO.jsp.





#### MISSOURI ELECTRONIC VITAL RECORDS

The purpose of the Missouri Electronic Vital Records (MoEVR) system is to support the registration of Missouri vital events for the Missouri Department of Health and Senior Services and other users such as funeral directors, attending physicians, medical examiners and birthing facilities. This system may be used only for the purpose for which it is provided. Any attempt to file fraudulent certificates of live birth, death or reports of fetal death is punishable in accordance with Missouri statutes.

By accessing this system, I agree to use this system only for the purpose of registering a Certificate of Live Birth, Certificate of Death or Report of Fetal Death for events occurring in the State of Missouri.

I understand that failure to adhere to the above agreement will result in loss of access to the MoEVR system. Any unauthorized access, misuse and/or disclosure of information may result in disciplinary action including, but not limited to, suspension or loss of individual or facility access privileges, an action for civil damages, or criminal charges.

LOGIN

# Logging into MoEVR

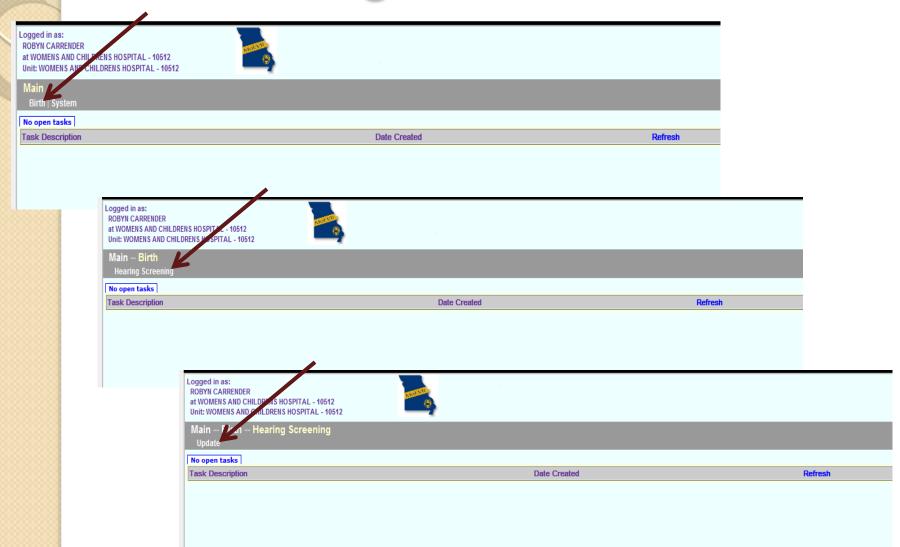




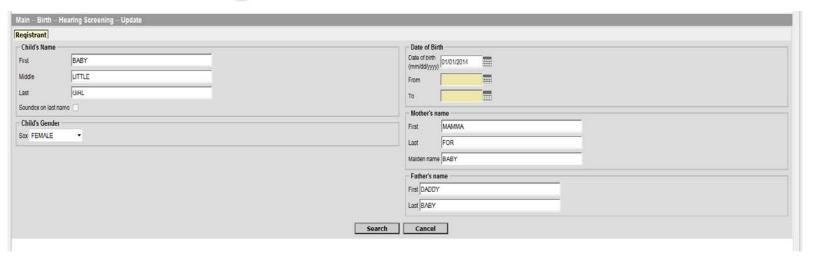




# Where to go next...



### Searching for Records



- The information provided in this form will be used to search birth records from your facility only.
- Birth certificate data must be entered into the MoEVR system prior to this time in order for the baby's information to be located.

### Searching for Records

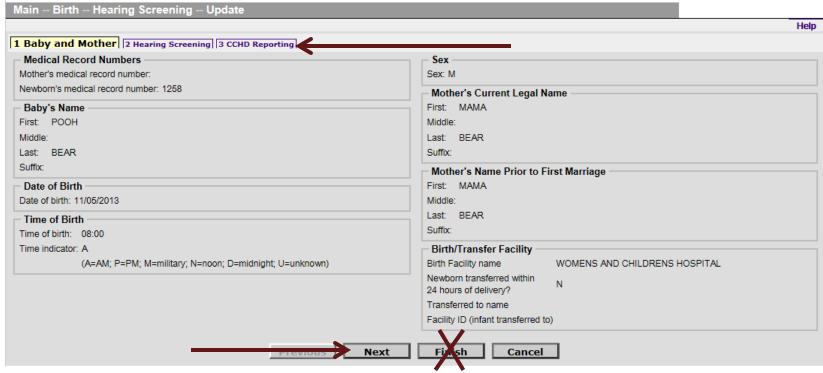


- A list of records will be shown. The child's first and last name, date of birth, sex, and mother's maiden name will appear on the screen.
- If your search criteria were broad, you may have a longer list of names to choose from.
- Click on "Details"

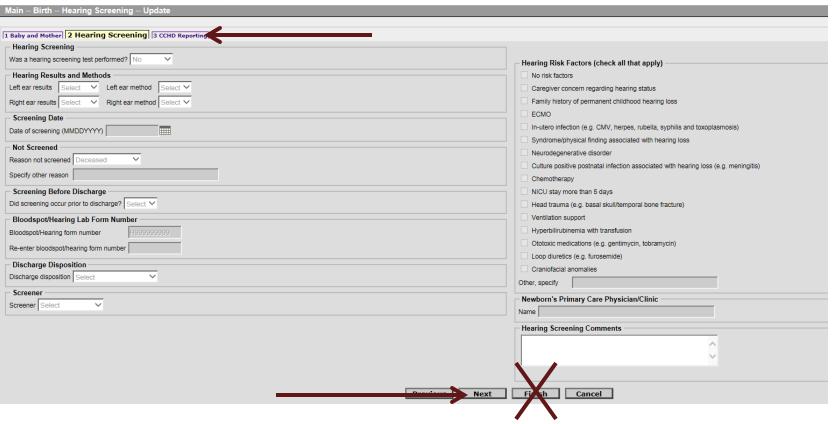
### Searching for Records



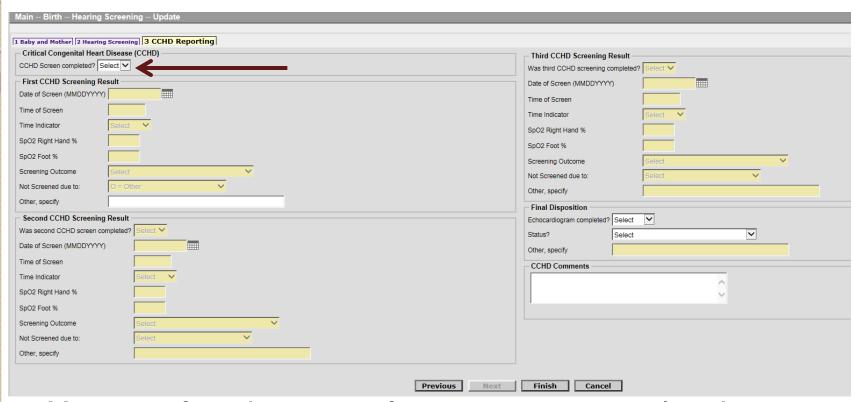
- This screen gives you the opportunity to review the record to ensure it is the correct baby.
- After verifying that you have the correct record, click "Continue."



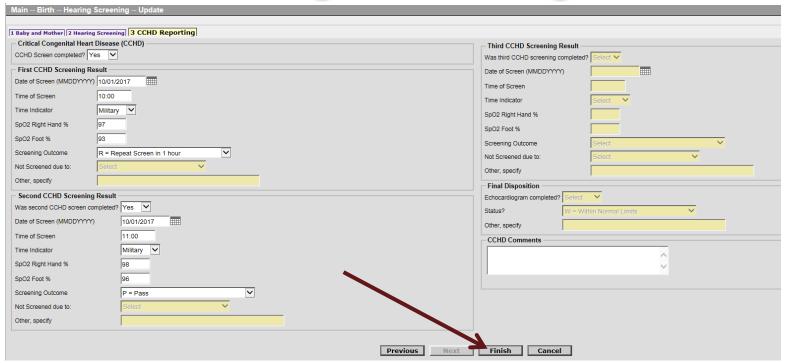
- "Cover page" for the data entry screens.
- You can navigate the data entry screens one of two ways:
  - Tabs at top of page
  - Buttons at bottom of page
- Click "Next." Do not click the finish button until you have entered in all screening data.



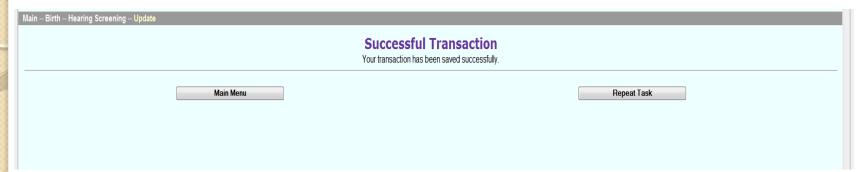
- This is the hearing screening data entry screen.
- If you do not have access to hearing screening data entry,
   you will not be able to manipulate the fields in this screen.
- Click on "Next."



- You must first document if screening was completed.
- Boxes that are yellow cannot be manipulated.
- Based on your documentation, certain fields will turn white to allow for further data entry.



- Please utilize the comments box to provide any clarifying information applicable to the baby's screening or disposition.
- Once all applicable data fields have been completed, click "Finish."
- Do not click Cancel. All data will be lost and you will have to start over.



- "Repeat Task" click to go back to the Registrant entry screen to search for another record
- "Main Menu" this will take you back to the very beginning



#### MISSOURI DEPARTMENT OF HEALTH AND SENIOR SERVICES BUREAU OF GENETICS AND HEALTHY CHILDHOOD

#### Critical Congenital Heart Disease (CCHD) Reporting Form

Instructions: Please complete the information below and submit to the Department of Health and Senior Services by one of the following methods: Mail – Bureau of Genetics and Healthy Childhood, PO Box 570, Jefferson City, MO 65109 or Fax – 573-751-6185

DEMOGRAPHIC INFORMATION										
NEWBORN'S NAME (LAST, FIRST)	DATE OF BIRTH	GENDER BIRTH ORDER  MALE (A+ OR S = SINGLE)  FEMALE	NEWBORN'S MED	DRIV'S MEDICAL RECORD NUMBER						
MOTHER'S NAME (LAST, FIRST)	NEWBORN'S BIRTH LOCATION HOSPITAL BIR' AMBULATORY SURG		NAME OF HOSPIT	NAME OF HOSPITAL, BIRTHING CENTER, AMBULATORY SURGICAL CENTER, OR MIDWIFE						
MOTHER'S STREET ADDRESS/P.O. BOX  OTY  STATE ZIP CODE										
FIRST CCHD SCREENING RESULT	SECOND CCHD SCREENING	RESULT	THIRD CCHD SCF	RD CCHD SCREENING RESULT						
First Screen Completed? Yes No	Second Screen Completed?	Yes No	Third Screen Compl	eted? Yes No						
Date of First Screen/_/  Time of First Screen: A.M. P.M.  Sp02 Right Hand%  Sp02 Foot%  First Screening Outcome:  Pass (screening complete)  Repeat Screen in 1 hour  Fail (refer for immediate evaluation)	Date of Second Screen Time of Second Screen Sp02 Right Hand  If Yes Sp02 Foot Second Screening Outc Pass (screening co Repeat Screen in 1 Fail (refer for imm	: A.M. P.M%some: omplete) L hour	Time of Th SpO2 Righ If Yes SpO2 Foot Third Scre	nird Screen// nird Screen: A.M. P.M.  It Hand%  It%  It						
Not Screened due to:  CCHD diagnosed prenatally  CCHD diagnosed clinically at birth  CCHD ruled out by echocardiogram  Transferred prior to screening  Parents refused screening  Expired  Other	Not Screened due to: Low value on prev Passed previous sc CCHD ruled out by Transferred prior t Parents refused sc Expired Other	echocardiogram to screening reening	Passed previous screen  CCHD ruled out by echocardiogram  Transferred prior to screening  Parents refused screening  Expired							
FINAL DISPOSITION	FINAL DISPOSITION									
Status: Within Normal Limits Pneumonia Unknown Other respiratory condition  Newborn transferred to referral hospital? No Yes, newborn was transferred to										

#### Critical Congenital Heart Disease Screening Table

Right Hand	Either Foot											
100	100	99	98	97	96	95	94	93	92	91	90	<90
99	100	99	98	97	96	95	94	93	92	91	90	<90
98	100	99	98	97	96	95	94	93	92	91	90	<90
97	100	99	98	97	96	95	94	93	92	91	90	<90
96	100	99	98	97	96	95	94	93	92	91	90	<90
95	100	99	98	97	96	95	94	93	92	91	90	<90
94	100	99	98	97	96	95	94	93	92	91	90	<90
93	100	99	98	97	96	95	94	93	92	91	90	<90
92	100	99	98	97	96	95	94	93	92	91	90	<90
91	100	99	98	97	96	95	94	93	92	91	90	<90
90	100	99	98	97	96	95	94	93	92	91	90	<90
<90	<90	<90	<90	<90	<90	<90	<90	<90	<90	<90	<90	<90

Pass: 95% or higher in the right hand and either foot AND a difference of 3% or less between the right hand and either foot.

**Repeat Screen**: 90-94% in the right hand and either foot or a difference of 4% or more between the right hand and either foot. Repeat screening in one hour. If third screen is still in the yellow, it is a fail and should be reported to the physician.

<u>Fail</u>: 89% or lower in the right hand or either foot (at any time) <u>OR</u> if the third screen is 90-94% in the right hand and either foot or a difference of 4% or more between the right hand and either foot. Failed screenings should always be reported to the physician.

### Next Steps

- Rules become effective November 30, 2017.
- After Rules are effective, additional information will be posted on the DHSS CCHD screening web page: www.health.mo.gov/cchd.
  - Final Rules for 19 CSR 40-12.010
  - Link to MoEVR
  - MoEVR Reporting User Manual
  - Paper reporting form
- Hospitals will need to determine who will be responsible for data entry. After November 30<sup>th</sup>, those individuals will need to submit requests for MoEVR CCHD data entry access.
- After receiving approval, they can begin entering screening data into MoEVR.

### Contact Info

Jami Kiesling, RN, BSN
Newborn Screening Program
Bureau of Genetics and Healthy Childhood

jami.kiesling@health.mo.gov

573-751-6266

