Critical Congenital Heart Disease Screening and Reporting

Missouri Department of Health and Senior Services
November 9, 2017
**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 defect-associated infant illness and death.

**Critical Congenital Heart Defects (CCHD):**

- Specific CHDs which require surgery or catheter intervention within the first year of life.
- About 1 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

2009
- AHA/AAP Statement

2010
- SACHDNC recommended adding CCHD Screening to the RUSP

2011
- Work group publication, guidelines endorsed by AAP, AHA, ACCF
- Endorsement from HHS Secretary to add CCHD screening to the RUSP

2012
- Survey of Missouri hospitals

2013
- Missouri Legislation passed - “Chloe’s Law”

2014
- CCHD screening required for all babies in Missouri
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

- 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
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.
Screening Guidelines

- Recommended guidelines endorsed by the AAP and AHA.
    - Article can be found at [www.health.mo.gov/cchd](http://www.health.mo.gov/cchd)
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 1 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.
Screening Guidelines

Measurement #2
Pulse Ox on Right Hand (RH) and One Foot 1 Hour After Measurement #1

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 1 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.
Screening Guidelines

Measurement #3
Pulse Ox on Right Hand (RH) and One Foot 1 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 (pre-ductal) AND either foot (post-ductal)

RH application site  +  Foot application site
MoEVR

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.
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 moevrsupport@health.mo.gov.

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.
Logging into MoEVR

1. Username: [Input]
   - Continue
   - Reset

2. What is the name of your favorite childhood friend?
   - Answer: [Input]
   - Continue
   - Reset

3. Please Note: Identify your image/key. Press cancel if they don't match.

4. Password: [Input]
   - Log In
   - Reset

Warning: You are about to gain access to the Missouri Department of Health and Senior Services, Bureau of Vital Records, MoEVR system. By proceeding, you are agreeing to maintain the confidentiality of all information as required by applicable state and federal laws. Any unauthorized access, release and/or disclosure of information may result in disciplinary action including, but not limited to, suspension or loss of individual or facility access privileges, or action for civil damages, or criminal charges.

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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.”
Documenting Screening Results

- “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.
Documenting Screening Results

- 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.”
Documenting Screening Results

- 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.
Documenting Screening Results

- 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.
Documenting Screening Results

- “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
# 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 – 573-751-5185

## DEMOGRAPHIC INFORMATION

<table>
<thead>
<tr>
<th>Newborn's Name (Last, First)</th>
<th>Date of Birth</th>
<th>Gender</th>
<th>Birth Order (4 or 3 = Single)</th>
<th>Newborn's Medical Record Number</th>
</tr>
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<tbody>
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<table>
<thead>
<tr>
<th>Mother's Name (Last, First)</th>
<th>Newborn's Birth Location</th>
<th>Name of Hospital/Birthing Center, Ambulatory Surgical Center, or Midwife</th>
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<tbody>
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<tr>
<th>Mother's Street Address, P.O. Box</th>
<th>City</th>
<th>State</th>
<th>Zip Code</th>
</tr>
</thead>
</table>

## FIRST CCHD SCREENING RESULT

<table>
<thead>
<tr>
<th>First Screen Completed?</th>
<th>Yes</th>
<th>No</th>
</tr>
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<tbody>
<tr>
<td>Date of First Screen</td>
<td>/ / / / / / / /</td>
<td>Time of First Screen: __ : __ A.M. P.M.</td>
</tr>
<tr>
<td>SpO2 Right Hand</td>
<td>%</td>
<td>%</td>
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<tr>
<td>SpO2 Foot</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>First Screening Outcome</td>
<td>Pass (screening complete)</td>
<td>Repeat Screening in 1 hour</td>
</tr>
</tbody>
</table>

## SECOND CCHD SCREENING RESULT

<table>
<thead>
<tr>
<th>Second Screen Completed?</th>
<th>Yes</th>
<th>No</th>
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<tr>
<td>Date of Second Screen</td>
<td>/ / / / / / / /</td>
<td>Time of Second Screen: __ : __ A.M. P.M.</td>
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<tr>
<td>SpO2 Right Hand</td>
<td>%</td>
<td>%</td>
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<tr>
<td>SpO2 Foot</td>
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<td>%</td>
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<tr>
<td>Second Screening Outcome</td>
<td>Pass (screening complete)</td>
<td>Repeat Screening in 1 hour</td>
</tr>
</tbody>
</table>

## THIRD CCHD SCREENING RESULT

<table>
<thead>
<tr>
<th>Third Screen Completed?</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Date of Third Screen</td>
<td>/ / / / / / / /</td>
<td>Time of Third Screen: __ : __ A.M. P.M.</td>
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<tr>
<td>SpO2 Right Hand</td>
<td>%</td>
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<td>SpO2 Foot</td>
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<tr>
<td>Third Screening Outcome</td>
<td>Pass (screening complete)</td>
<td>Repeat Screening in 1 hour</td>
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## FINAL DISPOSITION

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<th>Echocardiogram completed?</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
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<tr>
<td>Status</td>
<td>Within Normal Limits</td>
<td>Unknown</td>
<td>Pneumonia</td>
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<td>Delayed Transition</td>
<td>Seizure</td>
<td>Other Respiratory Condition</td>
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<td>Newborn transferred to referral hospital?</td>
<td>Yes, newborn was transferred to</td>
<td>No</td>
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<td></td>
<td>Critical Congenital Heart Disease</td>
<td>Other Condition</td>
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<td></td>
<td>Non-Critical Congenital Heart Disease</td>
<td>Other Condition</td>
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# Critical Congenital Heart Disease Screening Table

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**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.

**Fail:** 89% or lower in the right hand or either foot (at any time) OR 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

- After Rules are effective, additional information will be posted on the DHSS CCHD screening web page: [www.health.mo.gov/cchd](http://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 30th, 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

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Newborn Screening Program
Bureau of Genetics and Healthy Childhood
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573-751-6266