

Ohio Newborn Screening for Critical Congenital Heart Disease (CCHD) Frequently Asked Questions for Birth/Children's Hospital staff

Q: What legislation requires all babies to be screened for CCHD?

A: Ohio Revised Code (ORC) 3701.5010 and Ohio Administrative Code (OAC), also known as administrative rules, OAC 3701-54-01 to 3701-54-04.

Q: When does the screening and reporting law take effect?

A: October 1, 2014

NOTE: other revisions to the IPHIS birth certificate are visible right now, but those fields are NOT required to be reported until hospitals are trained by OPQC staff in early 2015. Only the CCHD tab is required to be used now.

Q: Does pulse oximetry screen for all heart defects?

A: No, only 7 specific critical congenital heart defects are targeted by the evidence to be screened for using pulse oximetry. Those disorders are:

- Hypoplastic Left Heart Syndrome
- Pulmonary Atresia
- Tetralogy of Fallot
- Total Anomalous Pulmonary Vessel Return
- Transposition of the Great Arteries
- Tricuspid Atresia
- Truncus Arteriosus

Q: How will birth hospitals report CCHD screening results to ODH?

A: A CCHD tab has been developed on the Ohio Vital Records IPHIS electronic birth certificate. The tab will be visible on Sept. 24, 2014, but is not required to be used until October 1, 2014.

Q: How will children's hospitals report CCHD screening results to ODH?

A: By completing and submitting the Critical Congenital Heart Disease Newborn Screening Report Form by email or fax. Email: Anna.Starr@odh.ohio.gov or Fax: to Anna Starr's attention at 614-564-2424.

Q: What are birth hospitals responsible to do for CCHD screening?

A:

- Designate a CCHD Coordinator and report that individual's contact information to Anna Starr at Anna.Starr@odh.ohio.gov. The CCHD Coordinator will serve as ODH's contact if there are questions about CCHD screening in your facility.
- The CCHD Coordinator will be responsible for 1) ensuring the hospital has a protocol for informing parents that a screening will take place; 2) ensuring that the screening takes place

prior to discharge according to the AAP screening algorithm; 3) ensuring the hospital has a protocol for evaluation/referring/transporting, etc. babies who fail their CCHD screening; and 4) ensuring the hospital has a policy in place for submitting screening results to ODH.

- The birth hospital should have policies in place for ensuring babies who fail the CCHD screening are immediately evaluated and receive appropriate diagnostic testing.
- The birth hospital should determine who will report CCHD screening results to ODH through the Ohio Vital Records IPHIS electronic birth certificate system. Either a Birth Clerk or a CCHD Clerk may enter the results.
- Birth hospitals with NICUs may elect to report like Children's Hospitals if babies spend significant time in the NICU before being discharged home.

Q: What are children's hospitals or hospitals with NICUs responsible to do for CCHD screening?

A:

- Designate a CCHD Coordinator and report that individual's contact information to Anna Starr at Anna.Starr@odh.ohio.gov. The CCHD Coordinator will serve as ODH's contact if there are questions about CCHD screening in your facility.
- The CCHD Coordinator will be responsible for 1) ensuring the hospital has a protocol for informing parents that a screening will take place; 2) ensuring that the screening takes place prior to discharge according to the AAP screening algorithm; and 3) ensuring the hospital has a policy in place for submitting screening results to ODH.
- The children's hospital should have policies in place for ensuring babies who fail the CCHD screening are immediately evaluated and receive appropriate diagnostic testing.
- The children's hospital should determine who will report CCHD screening results to ODH using the ODH Critical Congenital Heart Disease Newborn Screening Report Form via email or fax.

Q: What if parents object to the screening?

A: Parents may object to the screening per the legislation. Hospitals must keep documentation in the baby's medical record that the parent objected to the screening, and report the reason why the baby was not screened through the Ohio Vital Records IPHIS electronic birth certificate system or through the Critical Congenital Heart Disease Newborn Screening Report Form. ODH does not have an objection form for CCHD screening.

Q: Are there any reasons why a baby might not be screened prior to discharge?

A: Yes, the CCHD screening can be waived for the following reasons: 1) Parent objection to the screening; 2) Known diagnosis of a CCHD; 3) Baby discharged home on oxygen; 4) Baby transferred from birth hospital before screening could take place; 5) Technical problem with pulse oximeter.

For babies who are transferred to the NICU prior to being discharged home are monitored continuously. The Children's Hospital/NICU CCHD report form includes a response that the infant has received testing and does not have a CCHD diagnosis as a reason not screened.

Q: If a baby was diagnosed with a CCHD prenatally, are hospitals required to screen or report?

A: Screen = No. Babies with known diagnoses of CCHD do not need to be screened.
Report = Yes. In the Screening Disposition Section, please mark Known Dx of CCHD

Q: What if a baby is transferred to another hospital before screening can take place?

A: The receiving hospital is required to screen the baby when medically appropriate and prior to discharge.

Q: What if a baby is in the NICU for weeks or months? Is the tertiary care center still required to screen the baby?

A: Yes, the baby is still required to be screened when medically appropriate or before discharge. It may be easier for hospitals with NICUs to report screening results on the CCHD screening form rather than through IPHIS. It allows to report baby age in days rather than hours, and includes more reasons why a baby might not be screened since babies in the NICU are monitored more closely.

Q: Does the screening law apply if the baby was premature or low birth weight?

A: Yes, the baby must be screened when medically appropriate or prior to hospital discharge.

Q: If a newborn passes away and was not screened, are hospitals still required to report that the baby was not screened?

A: Yes, under the "Screening Disposition" area, mark OTHER on Reason Not Screened and write in the reason.

Q: Is ODH going to develop screening information for parents?

A: A screening fact sheet/information for parents is in development, but may not be available by October 1, 2014. Nearly all Ohio's children's hospitals have information about CCHD – please check with the children's hospital where your hospital may transfer babies. Also, please refer to the Resources document, as there are national resources from CDC, the American Academy of Pediatrics, Baby's First Test and more.

Q: What does the CCHD Updates Complete Field mean?

A: It is a Yes/No response as to whether the birth hospital is finished screening the baby, since babies may receive up to 3 screenings before a Pass or Fail is determined. Children's Hospitals and NICUs can disregard this field on the Screening Form – it will be removed in the next revision.

Q: What is the timeframe for hospitals to report CCHD screening results?

A: The legislation does not specify a timeframe. We request hospitals to submit the data within 10 days, consistent with Vital Statistics and Newborn Hearing Screening requirements.

Q: How long should hospitals keep documentation of CCHD screening?

A: This is a question and discussion for your hospital legal counsel. Hospitals should probably keep documentation that babies are screened as long as you keep any other records of infants in your hospital.