

Virginia Data Collection and Surveillance Critical Congenital Heart Disease Screening

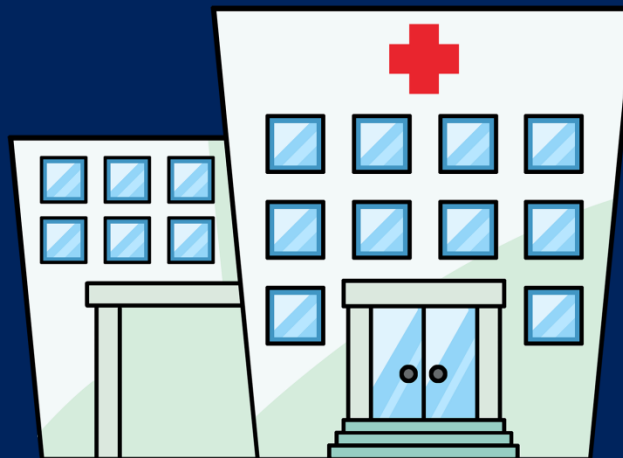


Kathy Moline RN, BSN, MA
Newborn Screening Supervisor
Virginia Department of Health



Year 1

- Focused on 6 demonstration project hospitals
- Education, site visits, provided clinical competency with a CCHD clinical expert, data collection
- Statewide survey





Year 2

- Original plan was to extend our demonstration project to another group of hospitals
- Statewide survey showed that all the VA hospitals were already screening, except for 1 (and this one is starting a program in 2014)
- Changed work plan to focus on provider education and surveillance



Virginia Surveillance

On January 1st, 2014 CCHD screening was added to the Virginia electronic birth certificate.





Virginia Surveillance

Training

- Invited nurse managers/educators and birth registrars from each of the birthing hospitals
- Invited midwives from known birth centers and home birth agencies
- Held 3 online live webinars in December 2013 and provided a recorded training



Virginia Surveillance

Child statistics page

- Optional information
- Under “Congenital Anomalies”
 - Cardiovascular System Anomalies
 - Pulse oximetry screening (choose positive or negative)
 - Critical congenital heart disease
 - Heart malformations (other than CCHD)

Virginia Surveillance



The screenshot displays a web application interface for Virginia Surveillance. On the left is a dark blue sidebar with a menu. The main content area is white and titled "Congenital Anomalies (check all that apply)".

Left Sidebar Menu:

- Client View
- Pregnancies
 - Search/New
 - Pregnancy Details
 - Pregnancy Summary
- Child Details
 - Live Birth Cert. Part I
 - Live Birth Cert. Part II
 - Live Birth Cert. Part III
 - Proof Of Birth
- Message Center
- Reports

Main Content Area:

Congenital Anomalies (check all that apply)

- 01 - Anencephaly
- 02 - Meningomyelocele/Spina bifida
- 03 - Hydrocephalus
- 04 - Microcephalus
- 05 - Other central nervous system anomalies
- 06 - Cardiovascular System anomalies
 - Pulse Oximetry Screening Result Positive ▾
 - Critical congenital heart disease
 - Head Malformations (other than Critical congenital heart disease)
- 07 - Other circulatory/respiratory anomalies
- 08 - Rectal atresia/stenosis
- 09 - Tracheo-esophageal fistula/Esophageal atresia

Annotations:

- A green box highlights the text "Enabled for births after implementation date" in the sidebar.
- A green arrow points from this text to the "Pulse Oximetry Screening Result" checkbox in the main content area.
- A red box highlights the "06 - Cardiovascular System anomalies" section and its sub-items.



Barriers and challenges

- Change is always a challenge – training started with why CCHD screening is important
- Registrars need to wait until after 24 hours to collect results
- Each hospital will chart results differently - registrars need to work with nurses to develop process to collect CCHD screening results



Chart Audits

- Will be doing chart audits for babies who have positive screenings, and a random sampling of negative screenings, to gather information and statistics about the screening and to make sure babies who are diagnosed are referred to the appropriate services



Chart Audits

- Screening details (review of pulse ox results, number of screenings, timing, etc)
- MD notification, tests ordered, specialists seen
- Transfer details (if baby is transferred)
- Diagnosis, treatment
- Maternal info



VACares

- Virginia Congenital Anomalies Reporting and Education System is a registry of children under age two with birth defects.
- The mission of VaCARES is to:
 - Collect data to evaluate possible causes of birth defects.
 - Improve the diagnosis and treatment of birth defects.
 - Establish a mechanism for informing families of children with birth defects and their physicians about available health resources.



VACares

- The development of VaCARES was mandated in 1985 and amended in 1986 and 2006 in the Code of Virginia, § 32.1-69.1. According to this mandate, hospitals are required to report cases of birth defects to VaCARES. The relevant information can be reported and reviewed without the prior written consent of the patient or family. The mandate also allows for review and evaluation of the system and activities.



Summary

- CCHD screening results added to the VA Electronic Birth certificate in December, hospitals trained
- Data collection started in January (Year 2 of the grant)
- First data reports run in February
- Will conduct chart audits of all positive screenings