



Utah Critical Congenital Heart Defect (CCHD) Screening Project

ADDITIONAL READING

[Implementing Recommended Screening for Critical Congenital Heart Disease](#)

[Public Health Roles for Birth Defects Monitoring Programs](#)

[Results from New Jersey CCHD Screening Program](#)

[STAR-G CCHD Fact Sheets](#)

[IBIS Indicators - CHDs](#)

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CCHD Screening: A Comprehensive Process

Implementing statewide CCHD screening using pulse oximetry presents clear challenges that must be addressed if such screening is to be successful. The actual procedure of applying a pulse oximetry probe to a baby’s skin and reading the results is only a very small part of a complex process.

CCHD screening requires developing a novel and potentially complex approach - from screening to confirmation. The current established newborn screening programs, including bloodspot (metabolic) and hearing screening, are different enough from CCHD screening that their methods and history can offer only partial guidance for how to move forward with this new process. The elements of this screening process are currently being addressed in the Utah Critical Congenital Heart Defect (CCHD) Screening Pilot Project, and are highlighted below:

Table 1. Utah Critical Congenital Heart Defect (CCHD) Screening Pilot Project Objectives

Objective:	Comment:
Validation of the screening test: cutoffs, impact of altitude	Pilot project is currently testing these elements; recommendations will follow pilots.
Development of follow-up procedures, including timely confirmatory testing and referrals	Best practices are being assessed and developed in the pilot project; a final document will be created and disseminated prior to statewide implementation.
Education and training providers	Preliminary provider education and training has been conducted at each pilot site; changes in the education/training protocol will be assessed and implemented prior to statewide implementation.
Education of families and public	Families involved at pilot sites are being educated about screening; changes to the family education protocol will be implemented prior to statewide implementation.
Appropriate and timely reporting to major stakeholders (state, providers, families)	Monthly data downloads are being captured by the Utah Birth Defect Network (UBDN) from each pilot site; discussions are underway regarding how best to capture these data once statewide implementation is in place.
Evaluation of outcomes (broadly defined and long-term: morbidity, mortality, costs)	Pilot project will assess these outcomes specifically for the participating pilot sites; establishment of an evaluation and monitoring plan will be important to be able to evaluate these outcomes in the long term.
Ongoing system assessment, evaluation and improvement	These elements will be vital for successful long-term implementation of CCHD screening. Gaps in the process will need to be identified and addressed by providing continuing education and/or training.

*CCHD screening requires developing a novel and potentially complex approach - from screening to confirmation.*

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# CCHD Screening Implementation Phone Survey to Be Conducted in December

The study coordinator for the Utah Critical Congenital Heart Defect (CCHD) Screening Pilot Project, Amy Nance, will be contacting the nursery managers of all birthing facilities in Utah to conduct a brief telephone survey during the month of December. The goals of the survey are to find ways to help birthing facilities plan for implementation of CCHD screening set to begin in October 2014, as well as assist with the evaluation of the process and create a loop for information feedback. This effort is meant to minimize problems with implementation, streamline training, and provide timely and helpful data for the birthing facility staff. If you would like more information or would like to set up a time to do the phone survey, please contact Amy Nance by phone at 801-883-4661 or by email at [aenance@utah.gov](mailto:aenance@utah.gov).

## CCHD Screening Resources

There are numerous online CCHD screening resources available for health care providers, families, and public health. Below, we have put together a few of these resources and tools to serve as a starting point for consideration of implementing CCHD screening.

### For Providers

- [Answers and Resources for Primary Care Pediatricians](#)
  - Website created by the American Academy of Pediatrics, including answers to frequently asked questions and a list of screening resources.
  - Link: <http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Newborn-Screening-for-CCHD.aspx>
- [Pulse Ox for Providers Video](#)
  - Heart Smart video series presented by Children's National Medical Center and Baby's First Test educating health care providers on screening for CCHDs.
  - Link: <http://www.youtube.com/watch?v=azmfWMXdrdg>
- [CCHD Program Toolkit](#)
  - A comprehensive toolkit created by Children's National Medical Center for implementing CCHD screening. Includes a program overview, screener training, education for parents and guardians, information on advocacy, and resource list. Version 2 of the toolkit is available online. Version 3 is available from the Utah Department of Health.
  - Link: <http://www.babysfirsttest.org/sites/default/files/CCHD%20Toolkit.pdf>

### For Families

- [Baby's First Test Website](#)
  - Website containing background information on CCHDs, educational videos for parents (in multiple languages), and follow-up testing, as well as information on early signs, treatment, expected outcomes, and causes.
  - Link: <http://www.babysfirsttest.org/newborn-screening/conditions/critical-congenital-heart-disease-cchd>
- [CCHD Fact Sheet](#)
  - A fact sheet for families on newborn CCHD screening produced by the Utah Department of Health for pilot screening at the University of Utah.
  - Link: [https://newsteps.org/sites/default/files/CHD%20Screening%20\\_U%20%281%29.pdf](https://newsteps.org/sites/default/files/CHD%20Screening%20_U%20%281%29.pdf)

### For Public Health

- [NewSTEPS](#)
  - Website created by the Association of Public Health Laboratories containing educational resources, legislative updates, data collection, and quality improvement tools.
  - Link: <https://newsteps.org/critical-congenital-heart-disease>
- [Wisconsin Shine Project](#)
  - Pilot project by the University of Wisconsin, Medical College of Wisconsin, and the State of Wisconsin designed to implement CCHD screening. Contains information for families, hospitals, home births as well as echo training modules.
  - Link: <http://wisconsinshine.org/>
- [Centers for Disease Control and Prevention](#)
  - CDC website with CCHD screening information, podcasts, webinars, and articles.
  - Link: <http://www.cdc.gov/ncbddd/pediatricgenetics/cchdscreening.Html>

Birth defects affect us all.



What effect will YOU have on birth defects?