

CCHD Screening



About CCHD screening tests:

CCHD stands for Critical Congenital Heart Defects (also sometimes named a less accurate term, Critical Congenital Heart Disease), a group of birth defect conditions which affects 18 out of 10,000 newborn babies. These conditions can be life-threatening.

Many babies with CCHD will have obvious symptoms; however, delays in diagnosis for a baby with CCHD, who appears well based upon a normal newborn exam, can result in serious additional damages to infants who may need immediate care, possibly including surgery.

The only screening test currently being recommended by the American Academy of Pediatrics (AAP) and the Center for Disease Control (CDC) uses a pulse oximeter to read the oxygen saturation levels in a newborn's extremities when the child is between 24 and 48 hours of age. This test is considered non-invasive, using light sensor probes on babies' hands and feet. Even when done properly, the test can have either false negative or false positive results, so is not a guarantee of diagnosis.

New Washington Regulations:

Recent legislation has mandated CCHD screening for all newborns in Washington, whether born in or out of a hospital. Parents always retain the right to decline testing, which the new law addresses. The law further outlines that midwives who lack the proper equipment to comply with AAP guidelines shall be exempt from performing the screening, shall inform their clients of that fact, and shall recommend in such case that the parents have their newborn screened for CCHD by a pediatric provider who can comply.

The new law creates several dilemmas:

1. There is no funding provided in the law for the training or equipment which is needed to comply with AAP recommendations and guidelines. The equipment required for compliance is an expensive hospital-grade pulse oximeter, and users are required to be trained in the nuances of using the machine to avoid false readings. At this time few midwives have either the training or the equipment to comply, and rural midwives delivering less than 10 babies per month may simply not have any time/profit to invest in either.
2. The time limit for screening is between 24 and 48 hours of age. In rural and underserved areas like southeast Washington, it may be physically impossible for your midwife to be at your home within that precise time frame.
3. Insurance is simply not paying anyone directly for this testing, so the costs must be borne by the parents, or under Medicaid must be absorbed by the

midwife as part of global maternity care. However, a separate visit to a pediatric clinic or local hospital for the same screening would be paid by insurance as a complex office or clinic visit, making that a more affordable option for most parents who desire the screening. Since that was always the case, the new law actually creates an awkward situation for providers and insurers alike, confusing both who is responsible for administering the screening and how it is to be billed.

Our current options:

At Highland Midwife Birth Services, we customarily carry an intermediate-level pulse oximeter which is adequate for us to identify the severity of some breathing and circulatory problems in newborns, and confer by phone with pediatric providers to determine whether transport is advised.

These are not the hospital-grade machines needed to comply with CCHD screening guidelines, but they may be capable of indicating a need to immediately obtain a higher level of care for many conditions which result in low oxygen saturation levels in the newborn, including CCHD. We are not opposed to providing that service with our existing machines whenever we possibly can, but cannot guarantee accuracy of the readings, and cannot guarantee our own physical availability during the 24-48 hour time frame.

Therefore we do not currently possess the ability to fully comply with the new regulation and are exempt from doing so, and must advise parents to obtain AAP-compliant CCHD screening from a pediatric provider. Parents are strongly advised to pre-arrange the screening (unless they decline), because timing is considered to be critical.

By initialing the Informed Choice Checklist, you agree to the following and select your option:

I have read and understand the above information, and had the opportunity to ask questions and do my own research. I understand that the time period for CCHD screening is limited, as is the accuracy of the test. I agree that I will not hold my midwife liable for CCHD screening, as she is exempt under the law due to inability to adequately comply.

Please also check or circle your choice(s) here, for your own recollection/records:

- I choose to NOT HAVE a CCHD screening test for my newborn.
- I choose to HAVE my midwife perform a pulse oximeter reading that may not meet Washington/AAP/CDC standards for CCHD screening.
- I choose to HAVE a CCHD screening test done by someone other than my midwife, such as my child's long-term pediatric provider, or a local hospital or clinic.