Critical Congenital Heart Disease (CCHD)

What is CCHD?
Critical Congenital Heart Disease (CCHD) is a medical problem that occurs when a baby’s heart or major blood vessels near the heart are not formed properly. The heart may not work well and there may not be enough oxygen in the blood.

What is Pulse Oximetry?
Pulse oximetry, sometimes called pulse ox, is used to screen babies for CCHD. Pulse oximetry is a test to determine the amount of oxygen in the baby’s blood and pulse rate. A low oxygen level in the blood might mean the heart is not working as well as it should. Every baby born in New York State will have a pulse oximetry test as part of screening after 24 hours of life.

Your baby has a low pulse oximetry screen, now what?
Some babies will have a low oxygen level reading. Your doctor will determine if further testing is needed, such as an electrocardiogram (EKG), x-ray and/or ultrasound of the heart (also called echocardiogram or heart echo). Your doctor may refer your baby to a pediatric heart specialist (cardiologist) and possibly other specialists. A low oxygen reading does not always mean that the baby has CCHD. Some healthy babies can have a low pulse oximetry reading while their heart and lungs are adjusting after birth. There could be other conditions that can cause your baby to have a low oximetry test result.

What if my baby has CCHD?
Treatment for CCHD varies but it can include medications, medical procedures or surgery. Your child’s medical team will recommend treatment and discuss options with other specialists.

Some babies with CCHD may have: bluish lips or skin, grunting sounds with breathing, fast breathing, poor feeding, extreme sleepiness or poor weight gain. If your baby has any of these signs, it is important you talk with your baby’s doctor about what to do. If these signs are new, call your baby’s doctor right away.

Additional Resources for Families about Congenital Heart Defects
American Heart Association:
www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/Congenital-Heart-Defects_UCM_001090_SubHomePage.jsp
Centers for Disease Control and Prevention’s National Center on Birth Defects and Developmental Disabilities:
www.cdc.gov/ncbddd/heartdefects/index.html
New York State Department of Health
www.health.ny.gov/diseases/congenital_malformations/cmrhome.htm