

From the Health Resources & Services Administration (HRSA)/Maternal & Child Health Bureau re: Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) recommendation to add critical congenital cyanotic heart disease (CCCHD) to the uniform newborn screening panel.

Although there are recognizable evidence gaps, there are compelling reasons for recommending screening newborns for critical congenital cyanotic heart disease (CCCHD). SACHDNC recommends the addition of screening for CCCHD to the recommended uniform screening panel with the understanding that the following activities will also take place in a timely manner: The National Institutes of Health shall fund research activities to determine the relationships among the screening technology, diagnostic processes, care provided, and the health outcomes of affected newborns with CCCHD as a result of prospective newborn screening; The Centers for Disease Control and Prevention shall fund surveillance activities to monitor disease link to infant mortality and other health outcomes; The Health Resources and Services Administration shall guide the development of screening standards and infrastructure needed for the implementation of a public health approach to point of service screening for CCCHD; The Health Resources and Services Administration shall fund the development of, in collaboration with public health and health care professional organizations and families, appropriate education and training materials for families and public health and health care professionals relevant to the screening and treatment of CCCHD.