



THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

April 20, 2011

R. Rodney Howell, M.D.
Committee Chairperson
Secretary's Advisory Committee on Heritable Disorders
in Newborns and Children
5600 Fishers Lane, room 18A19
Rockville, MD 20857

Dear Dr. Howell:

Thank you for your recent letter regarding the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children's recommendations and activities pertaining to the addition of Critical Congenital Cyanotic Heart Disease screening to the Recommended Uniform Screening Panel. I appreciate the Committee's ongoing efforts to improve care and services to newborns and children with heritable disorders.

As you noted in your letter, there are "recognizable evidence gaps" regarding screening for Critical Congenital Cyanotic Heart Disease. After consultation with HHS agency leadership, I have determined that the Advisory Committee's recommendations are not ready for adoption. However, because this is such an important issue, I am referring these recommendations to the newly established Interagency Coordinating Committee on Newborn and Child Screening (ICC) for additional review and input regarding implementation.

The ICC includes the National Institutes of Health, Centers for Disease Control and Prevention, Health Resources and Services Administration, Agency for Healthcare Research and Quality, and the Food and Drug Administration. ICC leadership will examine the evidence gaps described by the Advisory Committee, and propose a plan of action to address identification of effective screening technologies, development of diagnostic processes and protocols, education of providers and the public, and strengthening service infrastructure needs for follow-up and surveillance. The ICC will report this plan to me within 90 days, and I will keep you and the Advisory Committee informed.

Please accept my personal thanks to you and the members of the Advisory Committee for your valuable work to improve the health of our nation's infants and children.

Sincerely,

/s/

Kathleen Sebelius