



## DEPARTMENT OF HEALTH AND HUMAN SERVICES

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Secretary's Advisory Committee on Heritable  
Disorders in Newborns and Children  
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[www.hrsa.gov/heritabledisorderscommittee](http://www.hrsa.gov/heritabledisorderscommittee)

August 6, 2010

The Honorable Kathleen Sebelius  
Secretary of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, DC 20201

Dear Secretary Sebelius:

Each year, more than 4 million babies born in the United States are screened at birth by state newborn screening programs to detect some conditions that may threaten their long-term health. Of these, approximately 12,000 infants born each year are diagnosed with detectable and treatable disorders. If diagnosed early, these conditions can be successfully managed or treated to prevent severe and often lifelong health consequences. Contingency planning in the case of an emergency helps to ensure the availability of critical resources, the continuity of operations and sets standards for entities participating in the activation of the plan. Adhering to the established standards and maintaining continuity of testing and follow-up, plays a critical role in the screening, diagnosis, referral, and treatment of disorders identified in newborn screening, especially during a public health emergency.

Most sectors of government, as well as many successful corporations in the private sector, have developed plans to ensure continuity in the event of disaster or emergency. These plans are generally referred to as "Continuity of Operations," or COOP. A COOP for a newborn screening program and its public health laboratory should have two basic features: 1) provide a comprehensive, pre-identified list of all core testing, support activities, and supplies that must be maintained if the laboratory experiences a partial or complete operational disruption 2) provide a prearranged plan of action to ensure that all these core activities are continued without delay.

Section 5 of the *the Newborn Screening Saves Lives Act of 2008* (the Act) adds Section 1115 to the PHS Act, entitled **National Contingency Plan for Newborn Screening**. This section requires the Secretary, acting through the Centers for Disease Control and Prevention (CDC) and in consultation with the Health Resources and Services Administration (HRSA) and the State Departments of Health (or related agencies), to develop a national newborn screening contingency plan (CONPLAN) for use by a state, region, or consortia of states in the event of a public health emergency. This plan was required to be developed within 180 days of enactment of the legislation (by October 21, 2008) and is now complete. Both CDC and HRSA recently have approved the CONPLAN.

On May 13, 2010, the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) reviewed and approved the CONPLAN. The Committee supports the coordination of newborn screening emergency preparedness activities with current Department of Health and Human Services (HHS) emergency preparedness activities, and submits the following recommendation to the Secretary:

***In order to establish a comprehensive national all hazards approach to newborn screening incident response, the SACHDNC recommends that the Secretary of HHS coordinate newborn screening emergency preparedness activities, as defined in the CONPLAN, within HHS’s National Response Framework.***

Emergency preparedness planning and ongoing exercising of the plans are essential to ensure continuity of critical programs. Therefore, newborn screening and the CONPLAN should be a critical element of every state’s emergency preparedness plan.

Sincerely yours,

/S/

R. Rodney Howell, M.D.  
Chairperson

Attachment:

Tab A - NBS CONPLAN Final Signed - July 2010