



DEPARTMENT OF HEALTH & HUMAN SERVICES

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Advisory Committee on Heritable
Disorders and Genetic Diseases in
Newborns and Children
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APR 20 2005

The Honorable Michael O. Leavitt
Secretary of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Leavitt:

The Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children (the Committee) held their second meeting on September 22-23, 2004. One of the central tasks of this meeting was to review a draft report to the Health Resources and Services Administration (HRSA) on newborn screening from the American College of Medical Genetics (ACMG).

In 2002, the Maternal and Child Health Bureau (MCHB) of HRSA commissioned ACMG to review available information on newborn screening and to make recommendations based on the best scientific evidence for strengthening State based newborn screening programs in the country. The ACMG report contains a summary of the project, a review of the current and future landscape of newborn screening, the process used for the expert group's analysis and the expert group's recommendations. At the September meeting, a draft of the report was shared with the Committee for their review and comments.

The Committee met again on January 13 and 14, 2005 and received an update that the report was in a final form (The Committee has not yet reviewed the final report.). The Committee made the following recommendations, with a unanimous vote:

1. The ACMG report to HRSA be sent to the Secretary of Health and Human Services under Chairman Howell's signature on behalf of the Committee.
2. The ACMG report be released into the public domain as soon as possible for review and comment.
3. The Committee review, report, and make comments on the report as a Committee during the public comment period.
4. The Committee provides advice to the Secretary on the public comments received by the Secretary.

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A copy of the meeting summary and the public comments made at the September meeting are included for your review. Please know that the Committee stands ready to be of service to you to help strengthen newborn screening programs. Effective newborn screening programs play a significant role in improving the health of our Nation's children.

Sincerely yours,



R. Rodney Howell, M.D.
Chairperson
ACHDGDNC

Enclosures (1):

Tab A: Meeting Summary and Public Comments of the 2nd ACHDGDNC Meeting,
September 22-23, 2004