

APR - 4 2007

Advisory Committee on Heritable
Disorders and Genetic Diseases in
Newborns and Children
5600 Fishers Lane, Room 18A19
Rockville, Maryland 20857
(301) 443-1080 — Phone
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<http://mchb.hrsa.gov/screening/>

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

Dear Secretary Leavitt:

On December 19, 2006, the Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children (Committee) met in Washington, D.C. The Committee reviewed the work of its Subcommittee on Education and Training and made the following recommendation with a unanimous vote:

- the Secretary, HHS shall ***"develop and fund a mechanism to study the distribution of existing newborn screening educational materials and acquisition of knowledge about newborn screening by expectant parents in the context of the healthcare provider-patient relationship."***

The Committee formally endorsed the Subcommittee's emphasis on education that occurs within a prenatal clinical setting and by those professional organizations and entities most frequently involved in prenatal education such as obstetricians and nurse midwives. The fundamental message communicated is consistent with the current HHS newborn screening educational materials developed for health care professionals and expectant parents. The materials are developed primarily by the Health Resources and Services Administration (HRSA) in collaboration with the American College of Medical Genetics (ACMG), American College of Obstetricians and Gynecologists (ACOG), American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and the March of Dimes. In addition, the subcommittee reviewed various materials, such as newborn screening educational tools and documents developed by the National Library of Medicine and other health care and consumer organizations.

This is a significant shift of parental education from the post-natal period to parental education during the prenatal period so that parents will be informed in advance of the

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birth of their baby and have the opportunity to better understand and discuss the benefits of newborn screening.

Sincerely yours,

A handwritten signature in cursive script, appearing to read "R. Rodney Howell".

R. Rodney Howell, M.D.
Chairperson
ACHDGDNC