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

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Joseph A. Bocchini, Jr., M.D.
Committee Chairperson
Advisory Committee on Heritable
Disorders in Newborns and Children
5600 Fishers Lane
Room 18W68
Rockville, MD 20857

Dear Dr. Bocchini:

Thank you for your letter on behalf of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) regarding the ACHDNC's recommendations to add X-linked Adrenoleukodystrophy (X-ALD) to the Recommended Uniform Screening Panel (RUSP) and to provide federal funding to state newborn screening programs to implement the screening of X-ALD.

I would like to commend the ACHDNC on your evidence review that included an analysis of the benefits and harms of newborn screening for X-ALD as well as the capability of state newborn screening programs to offer comprehensive testing and follow-up services for infants identified with X-ALD. After reviewing the ACHDNC's report, *Newborn Screening for X-Linked Adrenoleukodystrophy (X-ALD): A Systematic Review of Evidence,* and taking into consideration the utility of current screening technologies, treatment for X-ALD, and the impact on public health systems, I accept the ACHDNC's recommendation to expand the RUSP to include the addition of X-ALD. As you may know the Affordable Care Act requires that most health plans cover without cost-sharing certain children's preventive services. Because the RUSP is a component of preventive services guidelines supported by the Health Resources and Services Administration, a condition added to the RUSP must be covered without cost sharing. I also want to clarify that the addition of X-ALD to the RUSP does not constitute a requirement for states to implement screening and is only a recommendation.

At this time, I am unable to identify new funding consistent with the ACHDNC's second recommendation to provide funding to state newborn screening programs to implement screening of X-ALD. However, I recognize the ongoing challenges that state newborn screening programs are experiencing in maintaining robust quality programs with the increasing demands of adding new conditions. This is why I have asked federal agencies to consider ways within their existing research and technical assistance resources to support state programs as they begin to implement comprehensive population-based screening for X-ALD.

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

Sincerely,

Sylvia M. Burwell