



For Immediate Release  
February 18, 2016

Contact: Natasha Bonhomme  
202-966-5557 x211  
[nbonhomme@geneticalliance.org](mailto:nbonhomme@geneticalliance.org)

### **X-ALD and MPS-1 Added to National Recommended Uniformed Screening Panel**

**WASHINGTON** – February 17, 2016 – Last year, the Advisory Committee for Heritable Disorders in Newborns and Children (ACHDNC) voted to recommend both X-Linked [Adrenoleukodystrophy \(X-ALD\)](#) and [Mucopolysaccharidosis type I \(MPS I\)](#) be added to the Recommended Uniform Newborn Screening Panel (RUSP). Yesterday, in a letter to Committee Chairperson Dr. Joseph Bocchini, the Secretary of Health and Human Services, Sylvia Burwell, announced her decision to accept these recommendations and add both X-ALD and MPS 1 to the RUSP. Although these conditions were added to the RUSP, the Secretary chose not to recommend any additional federal funding at this time to assist states in adding these conditions to their current programs.

“While Secretary Burwell’s decision to include X-ALD and MPS 1 marks a step for the expansion of newborn screening,” states Natasha F. Bonhomme “we look forward to the needed support for education, awareness-building, and support services for the families who will be detected.”

The addition of X-ALD and MPS 1 to the RUSP is the first addition to be made since Pompe was added last year. Addition to the RUSP means that, under the Affordable Care Act, these conditions must be covered by most health plans. There is a one-year grace period for health plans and insurers to adopt and implement this change in coverage. This addition will bring the total number of core conditions up from 32 to 34. For more information, please check the Advisory Committee on Heritable Disorders in Newborns and Children [website](#).

*About Baby's First Test*

*Baby's First Test is the nation's newborn screening clearinghouse. It informs and empowers families and healthcare providers throughout the newborn screening experience. The National Clearinghouse is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Cooperative Agreement no. U36MC16509 (Quality Assessment of the Newborn Screening System. Total award amount: \$2,900,000) to Genetic Alliance. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government. For more information, visit [BabysFirstTest.org](http://BabysFirstTest.org) and [Spanish.BabysFirstTest.org](http://Spanish.BabysFirstTest.org)).*

***About Genetic Alliance***

*Genetic Alliance engages individuals, families, and communities to transform health. Founded in 1986, it is the world's largest nonprofit health advocacy organization network. Genetic Alliance's network includes more than 1,200 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. For more information about Genetic Alliance, visit [www.geneticalliance.org](http://www.geneticalliance.org).*