

The GFPD and the Rare Disease Community Urges States to Take Advantage of Funding to Screen More Babies

Application Deadline is May 9

Every day, depending on what state a baby is born in, they may not be screened for conditions that have been recently added to the federally [recommended uniform screening panel](#) (RUSP). These conditions include: X-linked Adrenoleukodystrophy (X-ALD), Pompe Disease, Mucopolysaccharidosis Type I (MPS-I), and Spinal Muscular Atrophy (SMA). **Centers for Disease Control and Prevention (CDC) resources are now available to ensure babies across the United States get these recommended newborn screenings to prevent needless death and disability.**

12 patient organizations sent a letter urging nine states to expeditiously apply for this opportunity to help implement critical, federally recommended newborn screening. The states include: Alabama, Alaska, Nevada, Hawaii, Iowa, Montana, North Dakota, South Dakota, and Wyoming.

We understand funding can be a challenge, and this two-year grant opportunity could offer much needed resources. **The rare disease patient community urges states to apply today to build newborn screening capacity and save babies' lives in your state.**

The application deadline is May 9. More information on the grant opportunity can be found here: <https://www.grants.gov/web/grants/view-opportunity.html?oppld=335100>

###

The list of patient organizations includes: ALD Alliance, AMDA, Cure MLD, Cure SMA, The Global Foundation for Peroxisomal Disorders, Hunter's Hope Foundation, Leukodystrophy Newborn Screening Action Network, March of Dimes, Muscular Dystrophy Association, National MPS Society, United Leukodystrophy Foundation, X out ALD