

March 15, 2022

The Honorable Kay Ivey  
Alabama Governor  
600 Dexter Avenue  
Montgomery, AL 36130

Dear Governor Ivey,

The undersigned organizations representing rare disease families in your state write to alert you and your administration's health leadership to a federal grant opportunity now available to help state health departments implement critical, federally-recommended newborn screening. We urge you to expeditiously apply for the opportunity titled *Enhancing Disease Detection in Newborns: Building Capacity in Public Health Laboratories*, released by the Centers for Disease Control and Prevention (CDC) on March 8, 2022. **Note that the deadline to apply is May 8, 2022.**

Each year, 57,647 babies are born in our state, but unfortunately those babies are not yet currently being screened for three conditions on the recommended uniform screening panel (RUSP) including: X-linked Adrenoleukodystrophy (X-ALD), Pompe Disease, and Mucopolysaccharidosis Type I (MPS-I) resulting in preventable disability and death. CDC resources are now available to ensure all babies in Alabama get the recommended newborn screening to prevent needless death and disability and also save our health care system money in the long term.

We understand funding can be a challenge for newborn screening programs, and this two-year funding opportunity could offer much needed resources. Alabama can use the funding from this grant to either build capacity or enhance the existing screening program. More in the official announcement [here](#). **The rare disease patient community urges you to expeditiously apply to this special grant opportunity to build newborn screening capacity in Alabama and save babies' lives.**

If you are interested in learning more, we encourage you to attend the upcoming learning session hosted by CDC on the grant on March 16, 2022 at 2pm EST. Additionally, if you have any questions or concerns, please do not hesitate to reach out to Elisa Seeger with the ALD Alliance at [Elisa@aldalliance.org](mailto:Elisa@aldalliance.org). Thank you for your consideration.

Sincerely,

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

CC:

Dr. Scott Harris, Alabama State Health Officer