Support for Newborn Screening Implementation of New RUSP Disorders

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APHL is collaborating with the Colorado School of Public Health to implement the New Disorders Implementation Project.



A Program of the Association of Public Health Laboratories"

Goals

Goal 1: Assess needs and allocate resources for new condition integration in newborn screening systems

- Readiness Tool
- Via a competitive application process

Goal 2: Authority to implement screening

Goal 3: Implementation of laboratory and follow-up screening

- Provide resources and technical assistance to at least 15 state newborn screening programs
- To achieve full implementation of newborn screening for at least one of the new conditions (Pompe, MPS-1 and/or, X-ALD) by September 2018.

Goal 4: Community, parent, and provider education







Colorado School of PUBLIC HEALTH



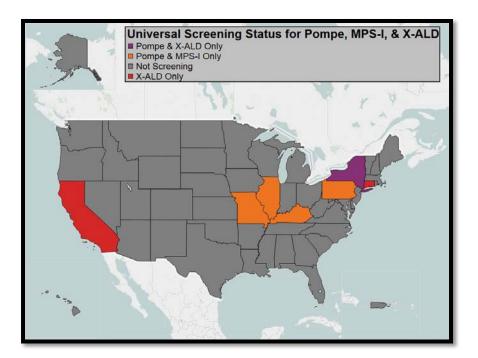




State of NBS for Pompe, X-ALD, MPS-1

Pompe Disease added to RUSP in March 2015

- 5 states currently screening
- MPS-1 added to RUSP in February 2016
 - 4 states currently screening
- **X-ALD** added to RUSP in February 2016
 - 3 states currently screening





Technical Assistance

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- New Disorders Work Group
- National, Monthly Educational Webinars
- National, In-Person Meeting



Technical Assistance (Discussion)

- Role in LTFU
- Are we capturing everything we need to measure (delayed onset, variants of unknown significance, etc.)
- How can we be proactive about addressing possible future disorders added to the RUSP?
- Technical Assistance in the Future? What does this look like?

