



Support for Newborn Screening Implementation of New RUSP Disorders

The development of this request for proposals application was supported by Cooperative Agreement Number UG9MC30369 from the Health Resources and Services Administration (HRSA). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of HRSA.

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



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



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APHL ASSOCIATION OF
PUBLIC HEALTH LABORATORIES

Colorado School of
PUBLIC HEALTH



baby's
first test



NBSTRN

Newborn Screening
Translational Research
Network



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Technical Assistance

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



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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?



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