

How the RUSP works

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Make today a breakthrough.

What is the RUSP?

- Recommended Uniform Screening Panel
- Developed by the Secretary's Advisory Committee on Heritable Disorders in Children and Infants

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Helena Hernandez, 11/9/2018

What's the Advisory Committee?

- Panel of experts in genetics, maternal and child health, pediatrics, testing, and public health
- Federal newborn screening law gives it authority to make recommendations about what conditions states should include in their screening panels.

RUSP Process

- **Submit Nomination:** Multi-disciplinary teams work together to submit nominations for conditions for inclusion on the RUSP.
- **Nomination and Prioritization Workgroup:** Committee's Nomination & Prioritization (N&P) Workgroup reviews the Nomination Package and compiles a summary for Committee consideration. The Committee decides if there is sufficient evidence available to assign the condition to the external Condition Review Workgroup.
- **Condition Review Workgroup:** The external Condition Review Workgroup completes a evidence-based review, provides updates, and presents a final report to the Committee.
- **Committee Deliberations and Votes:** The Committee evaluates evidence based on decision matrix to guide to recommend or not recommend condition to the RUSP, for final consideration by the Secretary of Health and Human Services.
- **Timeline for Committee Decision:** Reauthorization of NBS Saves Lives Act gives Committee 9 months to make decision on application once moved to Review Group.
- **Final Decision:** HHS Secretary has 120 days to formally approve recommendation

RUSP Considerations

- Is there a measurable benefit to screening newborns, rather than waiting for clinical diagnosis?
- Is there a reliable, affordable test?
- Is there an effective treatment?

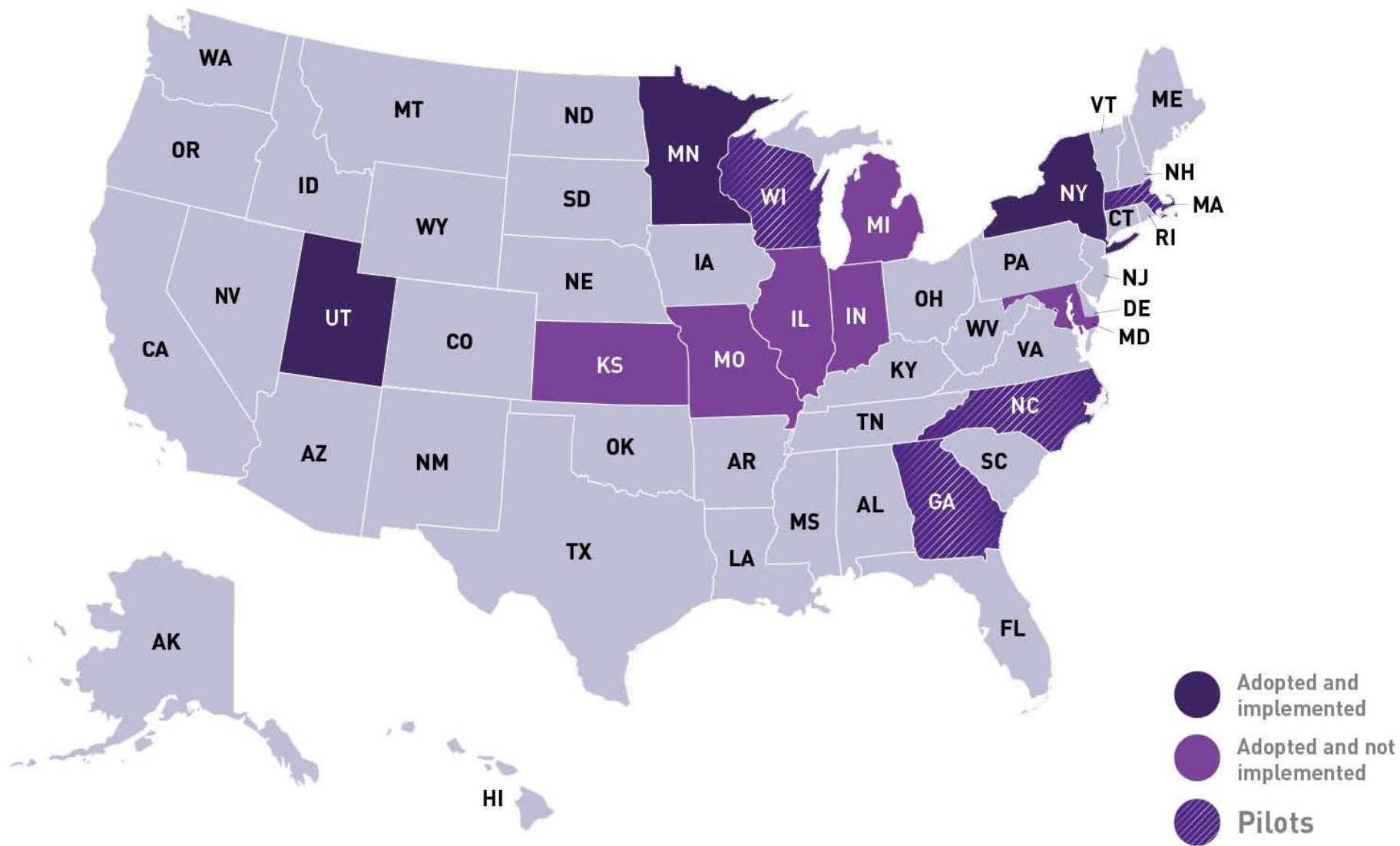
SMA ADDED TO THE RUSP!



Then what?

- **Recommended Uniform Screening Panel**
 - Not Required
- Need to implement in all 50 states
 - 50 different processes

cure SMA Newborn Screening Programs



Lessons Learned (and still learning!)

- Partnerships
- Good science
- Build coalitions
- Play the long game
- Engage patients and/or families

THANK YOU!

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