

Critical Congenital Heart Disease Newborn Screening National Implementation and Data Reporting

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NewSTEPS

February 1, 2013



Critical Congenital Heart Disease Newborn Screening

- CCHD added to Recommended Uniform Screening Panel in September 2011
- Demonstration Project Funding from HRSA funded 6 projects (2012-2015, ~\$300,000/year)
- State approaches to implementation are varied

Overview

- Current status of CCHD screening
 - Legislative Needs and Progress
 - Pilot Studies and Local Implementation
 - Challenges and Barriers
- Data collection efforts
- The next steps

Sources of Data

- Newborn Coalition
- NewSTEPS Survey of states completed in January 2013
- Regional Genetics Collaboratives (HRSA)

Legislative Process

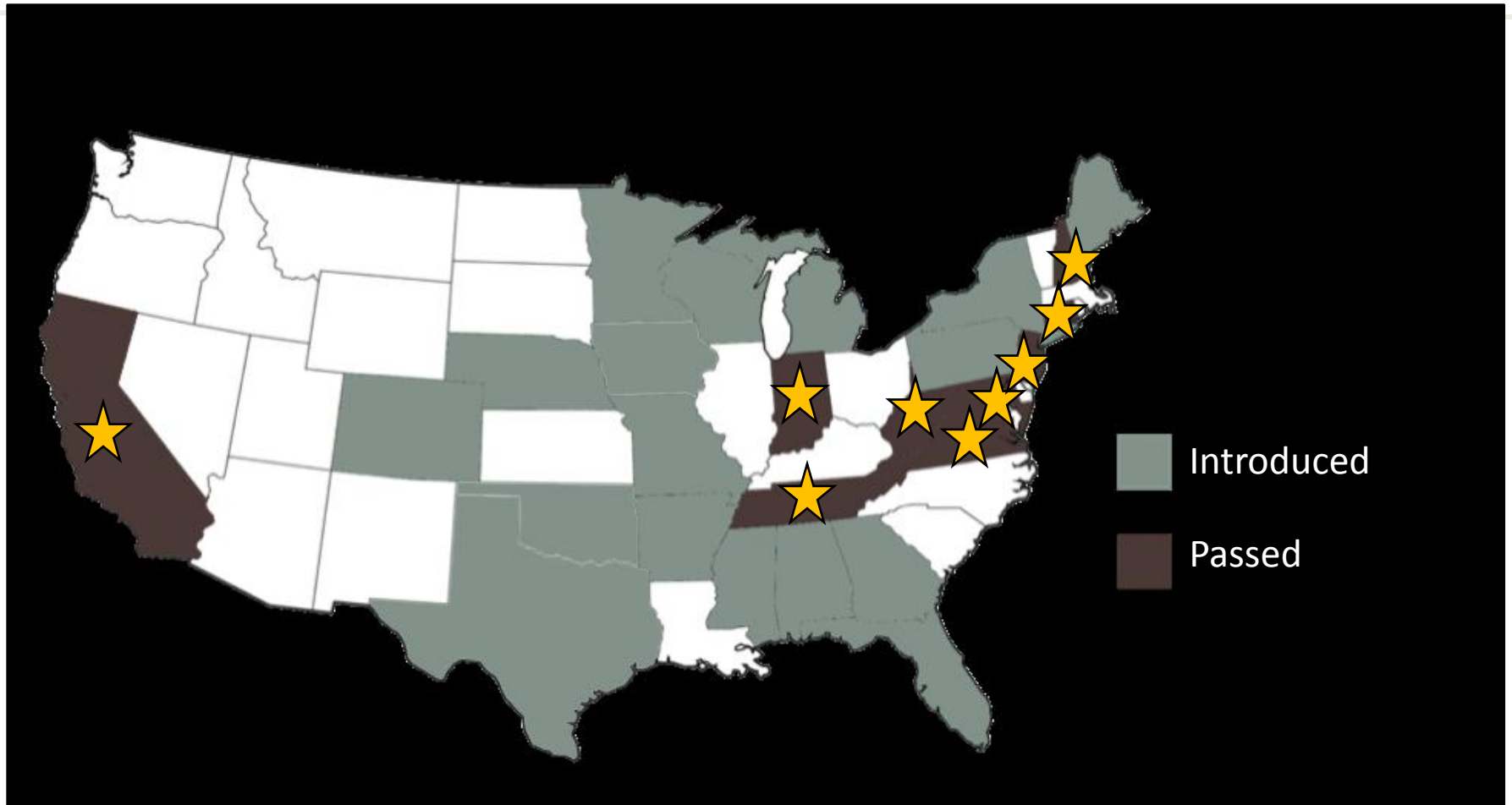
Requirements for adding new conditions vary by state (Responses received from 43 states)

- Legislative action required in 23/43 (53%)
- Board of health/advisory committee in 20/43 (47%)

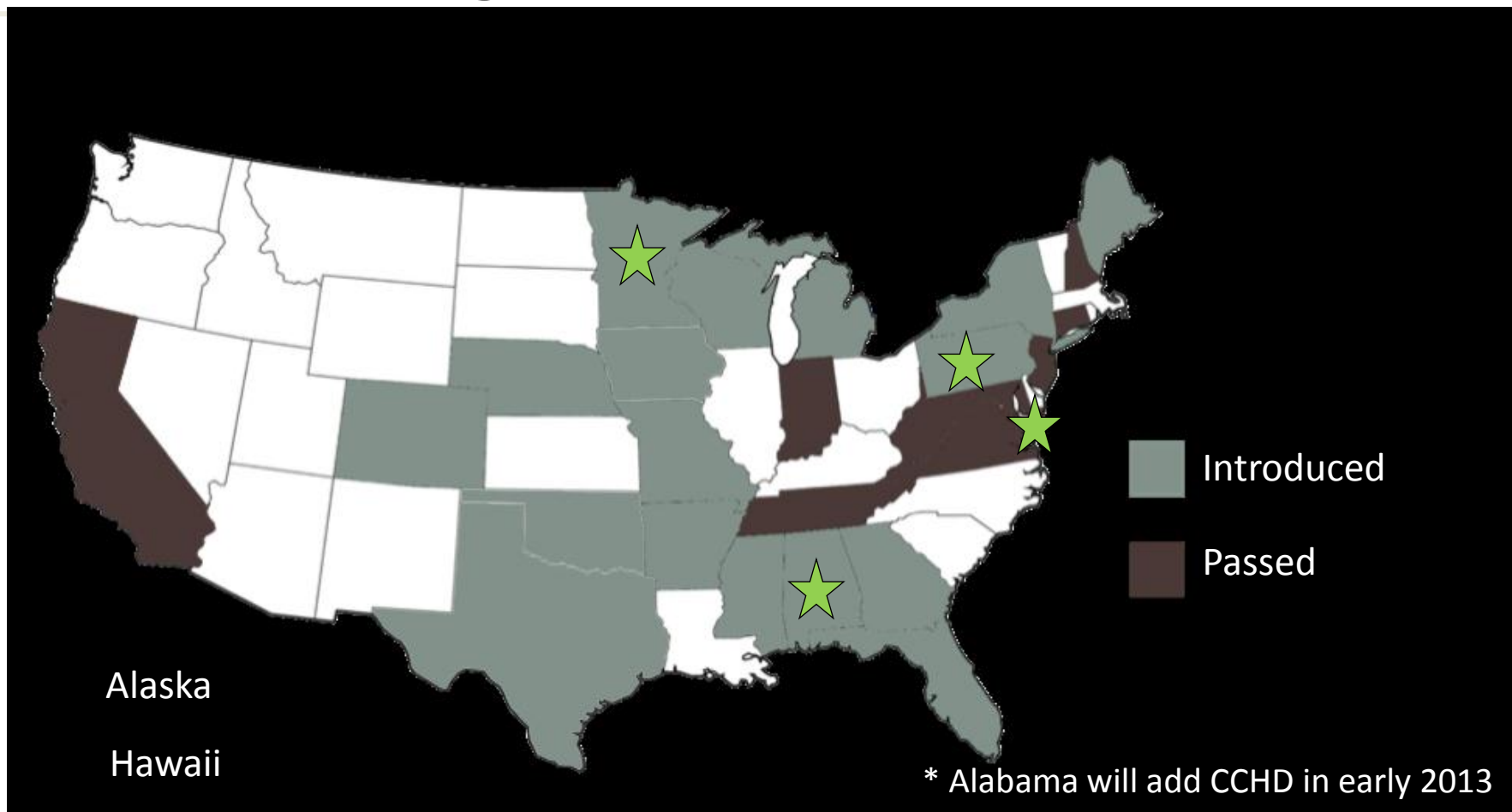
Legislation has been introduced in 29/50 states

- Pending in current legislative sessions in 10
- Others have tabled discussion awaiting more information
- Only 2/28 states mention funding attached to legislation

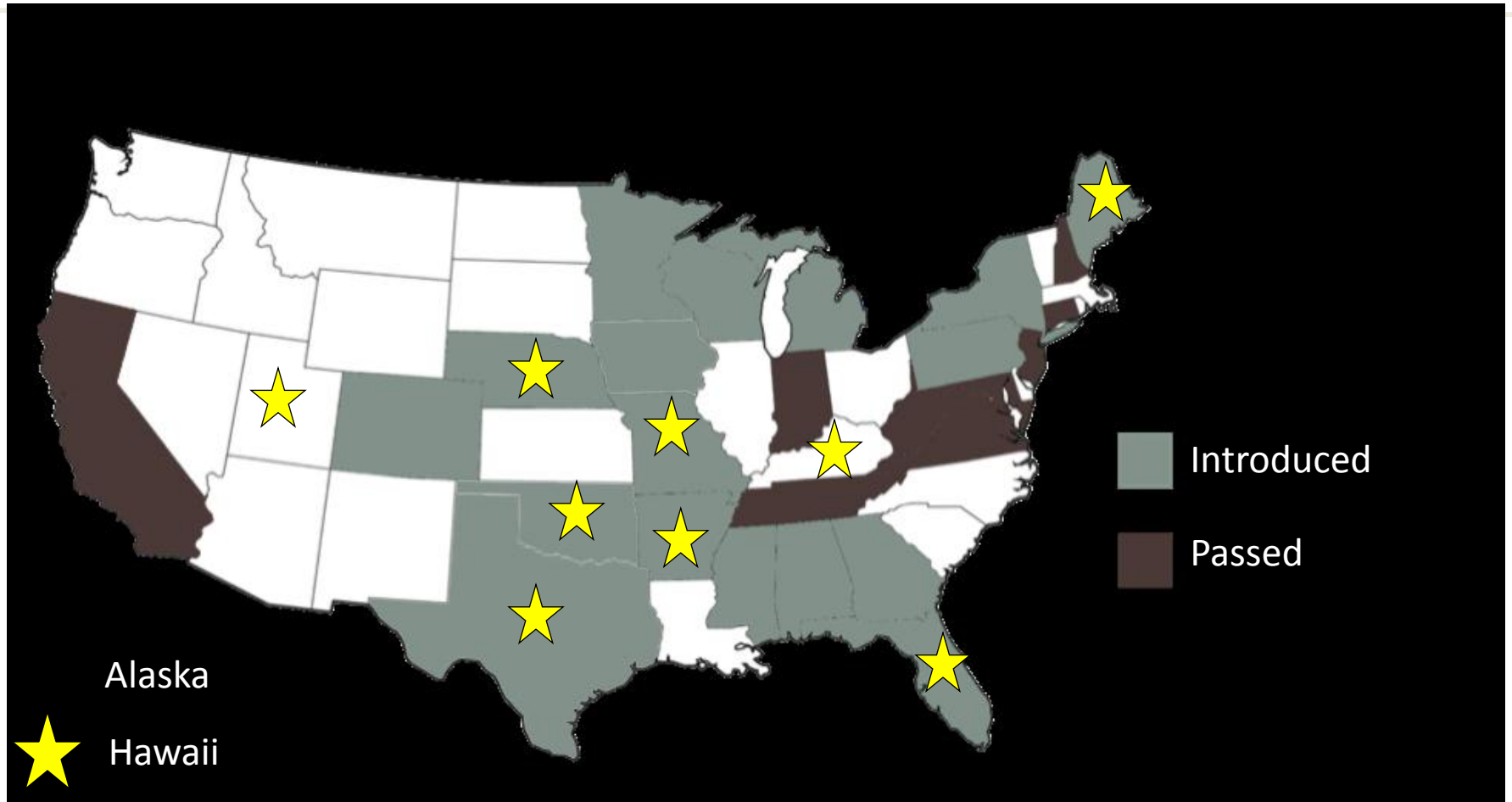
Status of Successful Legislation to implement CCHD Screening



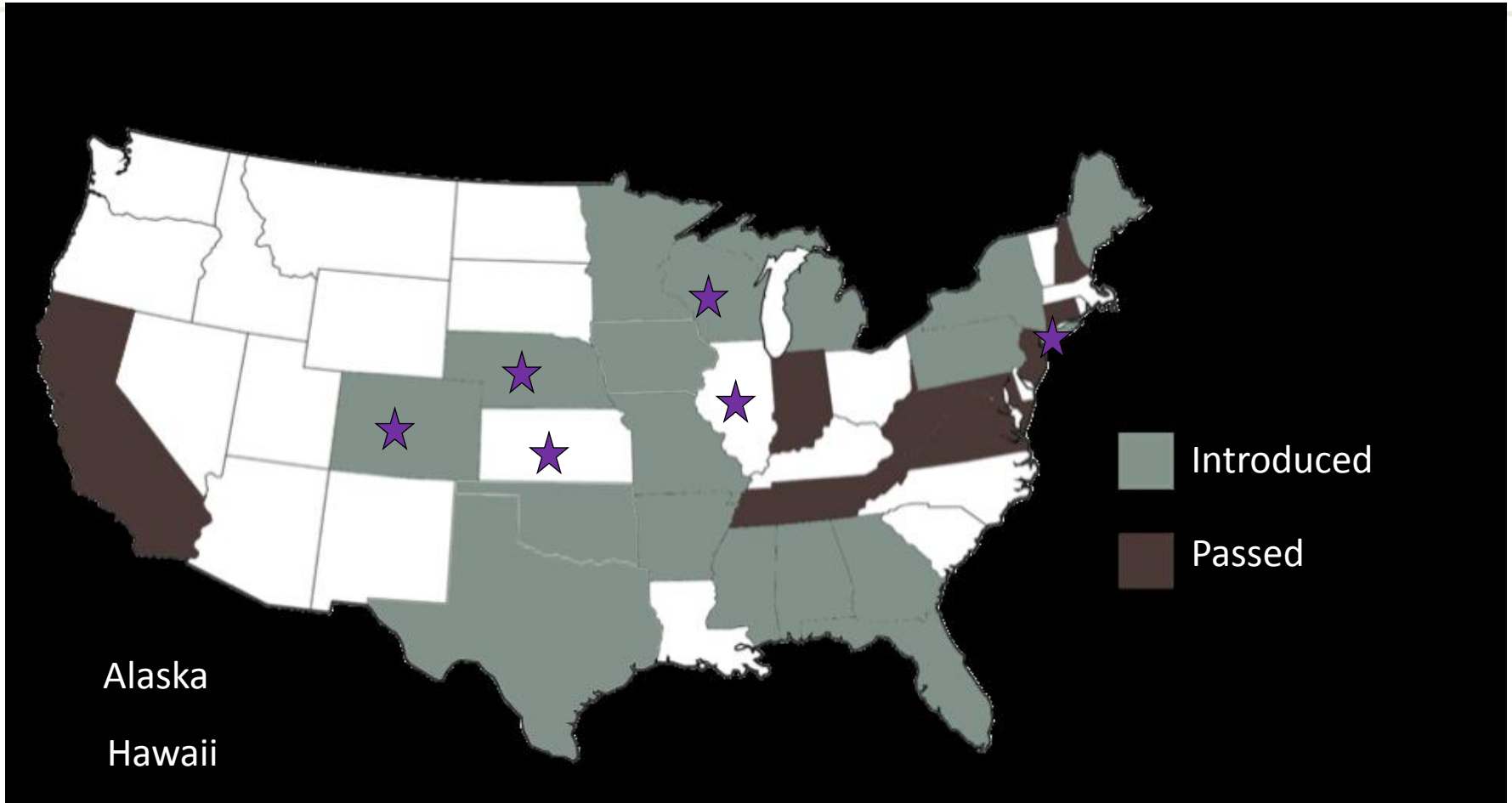
Status of Mandated CCHD Screening through other mechanisms



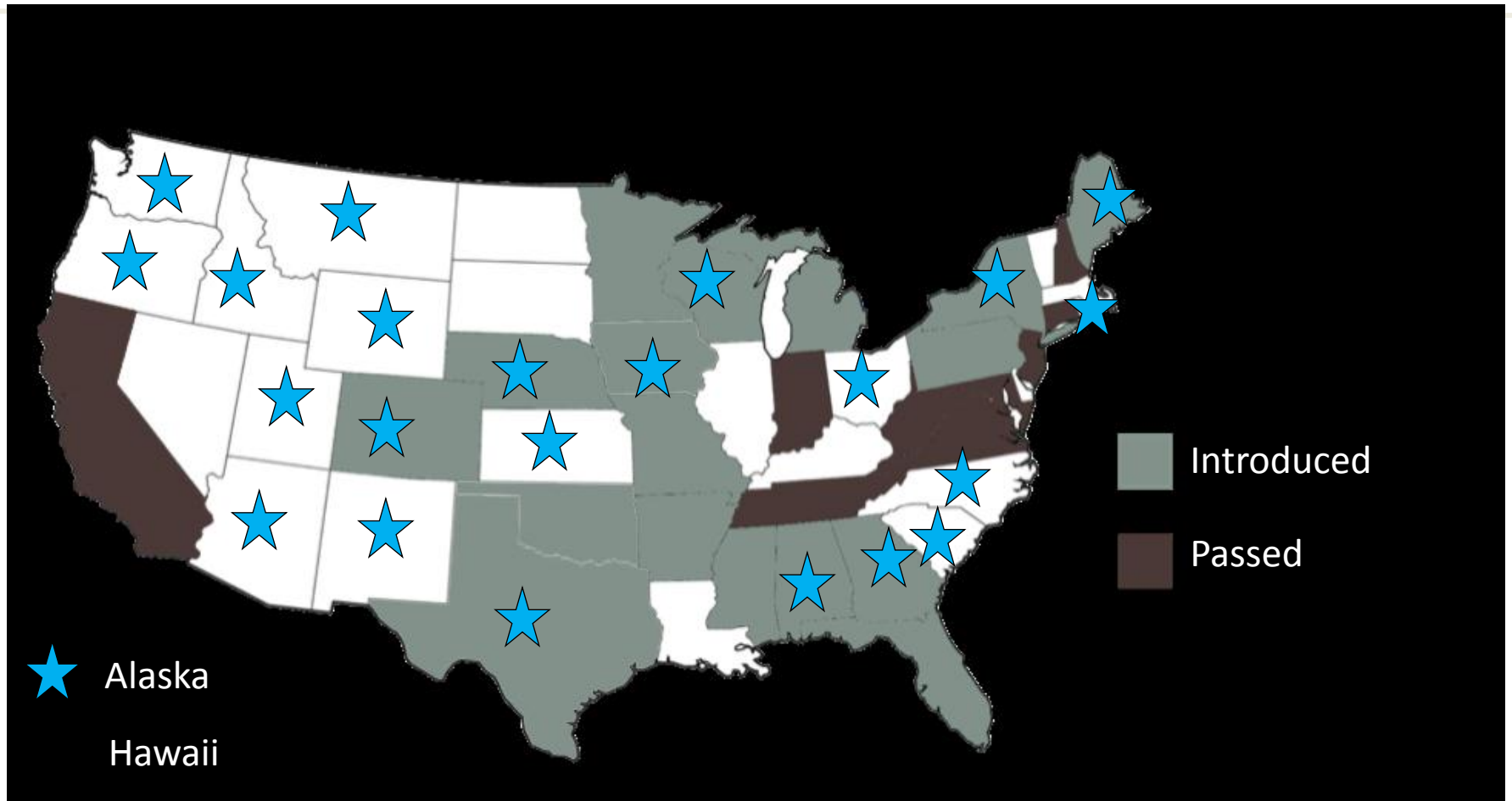
Status of Legislation Introduction for CCHD Screening – Active Bills



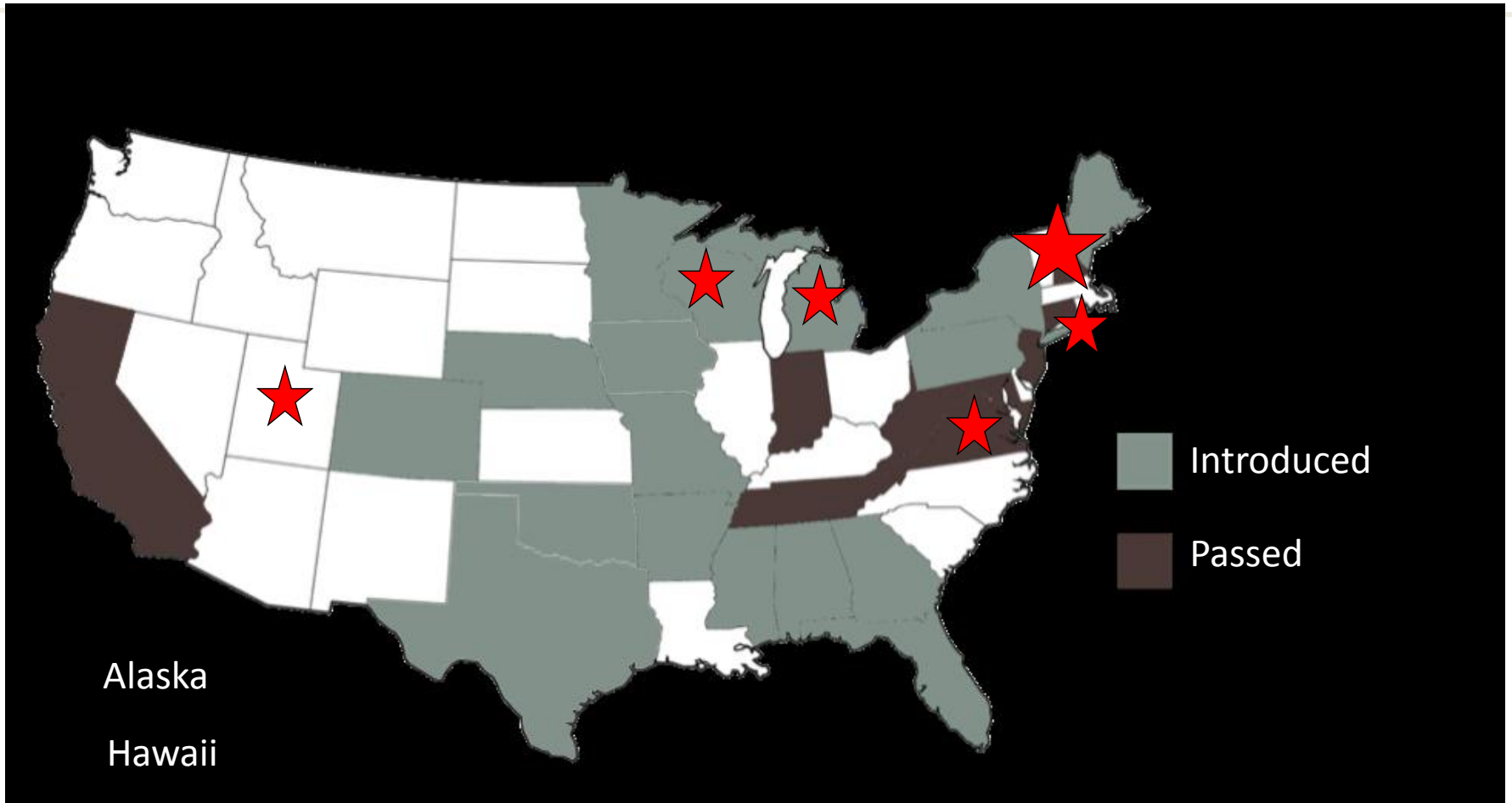
Activity in State NBS Committees



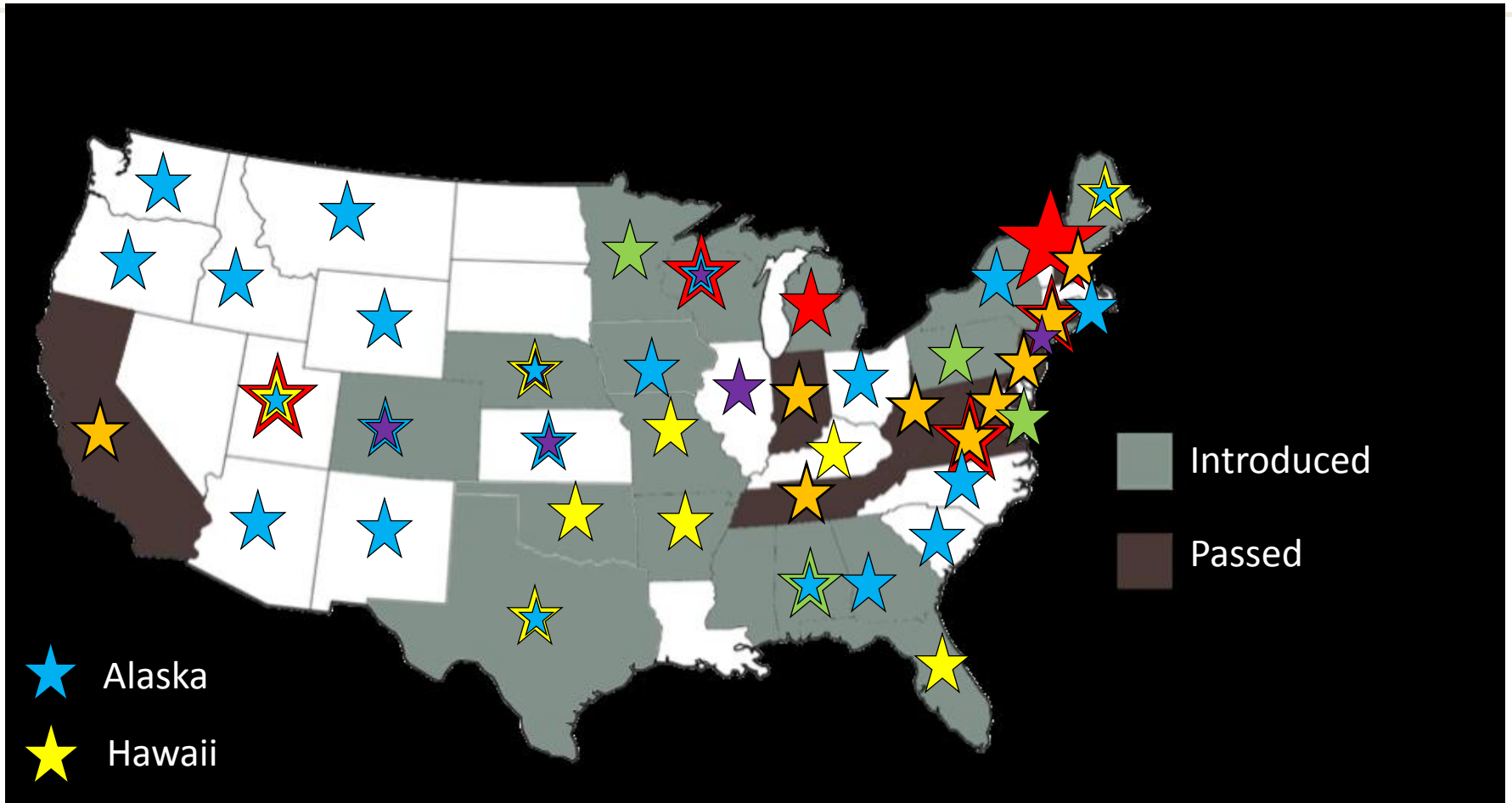
Status of Pilot Studies and Localized Hospitals CCHD Screening (as reported to Health Departments)



Location of HRSA Pilot Demonstration Projects



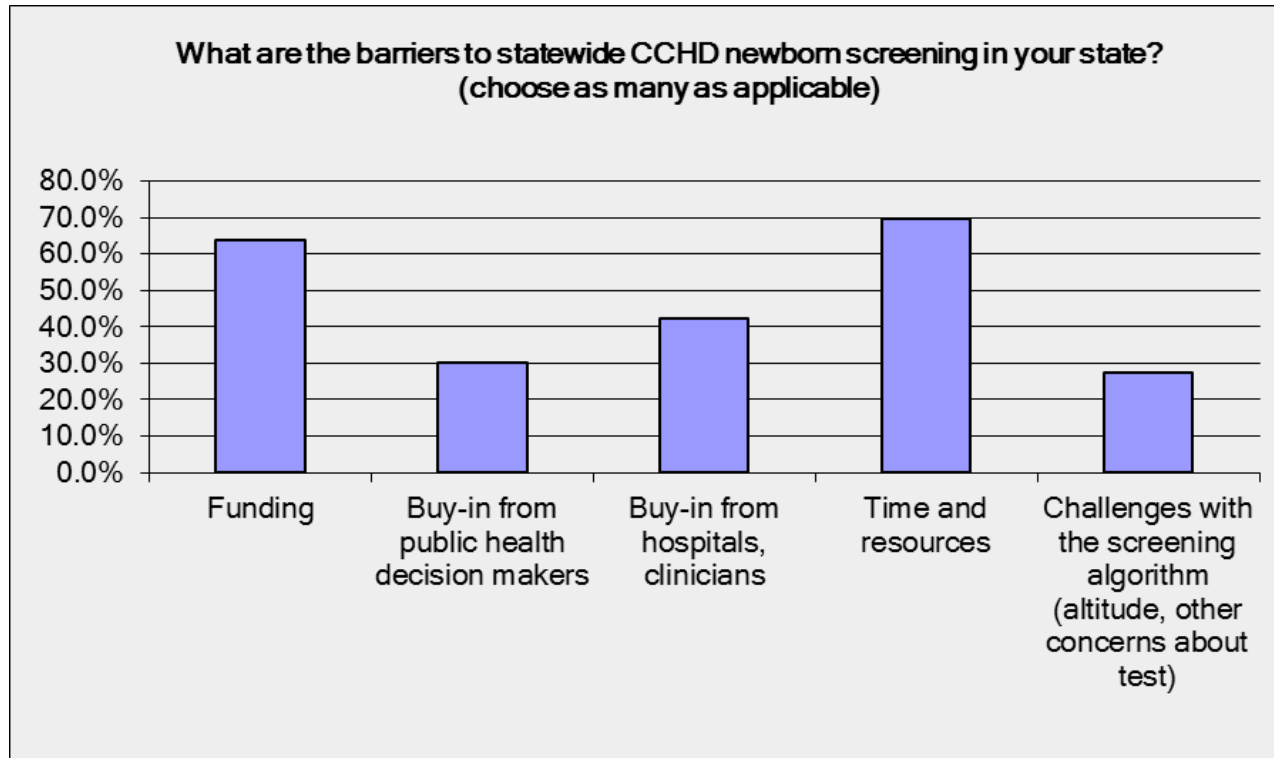
All CCHD Activities



Challenges and Barriers

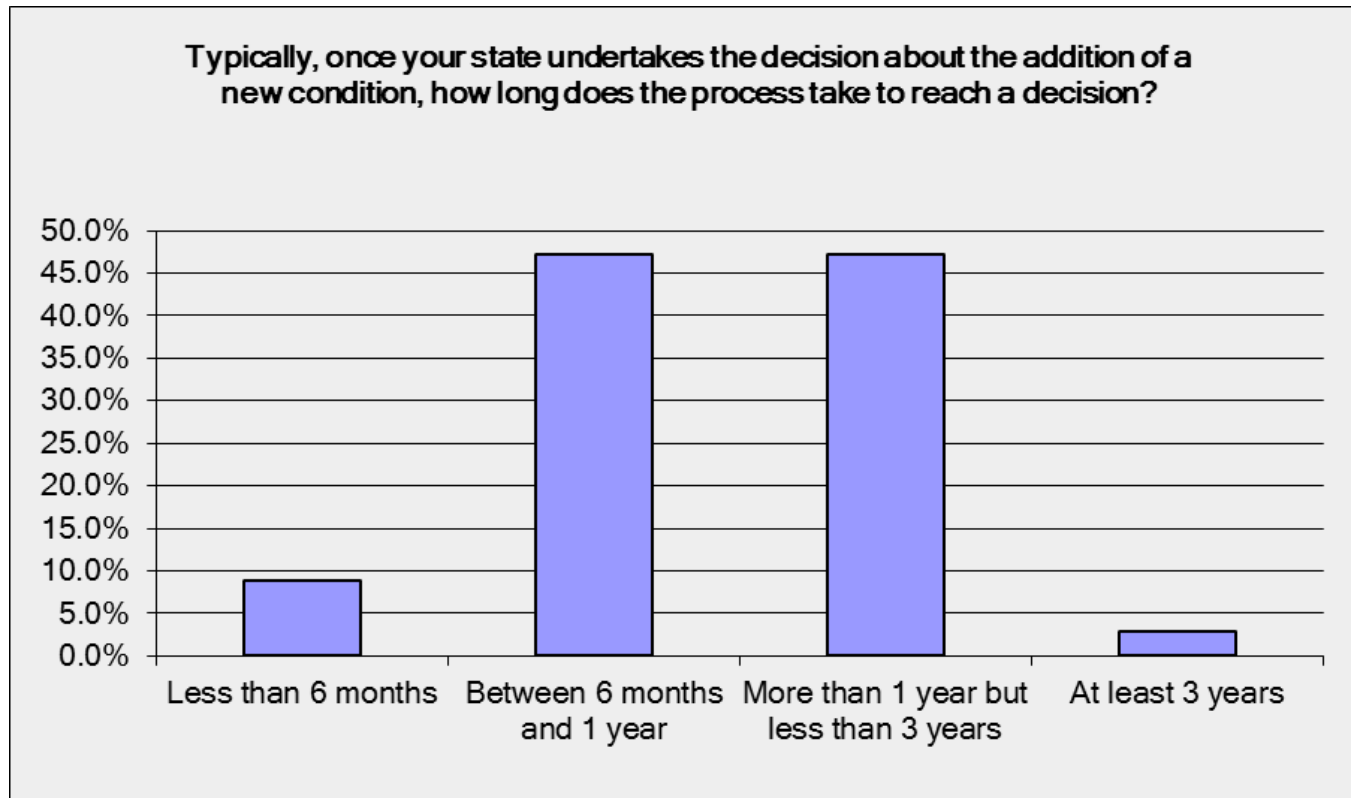
- Funding
 - Set up of data systems
 - Development of surveillance system
- Convincing Public Health Decision Makers
 - Algorithm
 - Resources

Challenges and Barriers to Implementation



Based on Responses from individuals in 41 states

Timing of Implementation



Based on Responses from individuals in 41 states

Determining the 'minimal data set' for state collection

- What is the role of Public Health?
 - Quality assurance, surveillance, quality improvement
 - Types of data to be collected
 - Testing done/not done
 - Data on babies who failed screening
 - All data on all screens
- National partners joining efforts for data
 - Centers for Disease Control and Prevention (CDC)
 - Association of Maternal and Child Health Programs (AMCHP)
 - National Library of Medicine (NLM)
 - American College of Medical Genetics (ACMG)
 - NewSTEPs (Newborn Screening Technical assistance and Evaluation Program)

Data collection locally and nationally

- Developing data systems for collection at the state level
 - Modifications of existing systems
 - EHDI (Early Hearing Detection and Intervention)
 - Electronic Birth Certificate
 - Commercial systems
 - New data collection systems
- NewSTEPs national newborn screening repository
 - Data on babies with disorders identified by newborn screens
 - Quality indicators to track metrics in state newborn screening programs

Current Resources for States and Next Steps

- Technical assistance
 - Monthly webinars with timely topics at ‘advanced’ and ‘basic’ levels
 - National Children’s Medical Center online resource
http://www.childrenshealthcommunities.org/pulse_ox
 - Listserv to post questions and offer solutions
 - NewSTEPs identifying resources and partners to assist states

Questions
