

The State of Newborn Screening Systems

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www.newsteps.org



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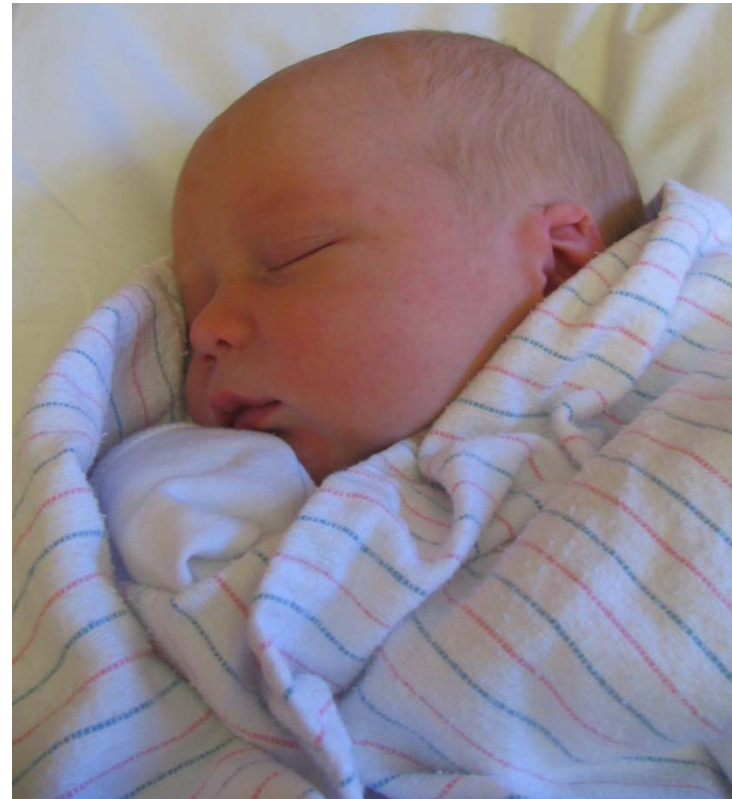


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“The only constant in newborn screening is the baby”

- Harry Hannon, PhD



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Newborn Screening Systems in the United States

- Fifty years of newborn screening
- One disorder in 1963, dozens in 2014



NBS in the News

JOURNAL SENTINEL



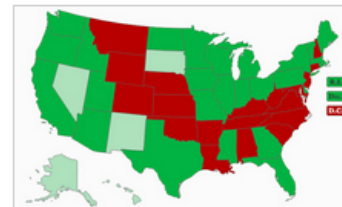
A JOURNAL SENTINEL WATCHDOG REPORT

Deadly Delays

The nation's newborn screening programs depend on speed and science to save babies from rare diseases. But thousands of hospitals fall short, deadly delays are ignored and failures are hidden from public view — while babies and their families suffer.

Published Nov. 16, 2013

Delays at hospitals across country undermine newborn screening programs



Interactive: See how states compare and search for problem hospitals



Colton Hidde: Testing delay puts newborn's life in jeopardy



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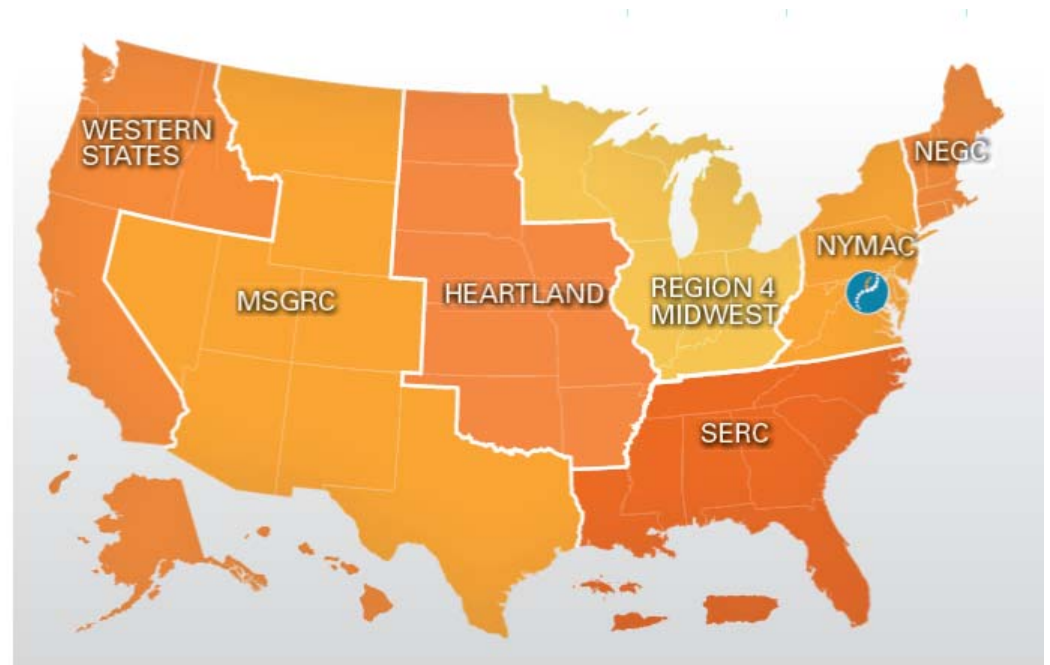
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The state of newborn screening systems is strong

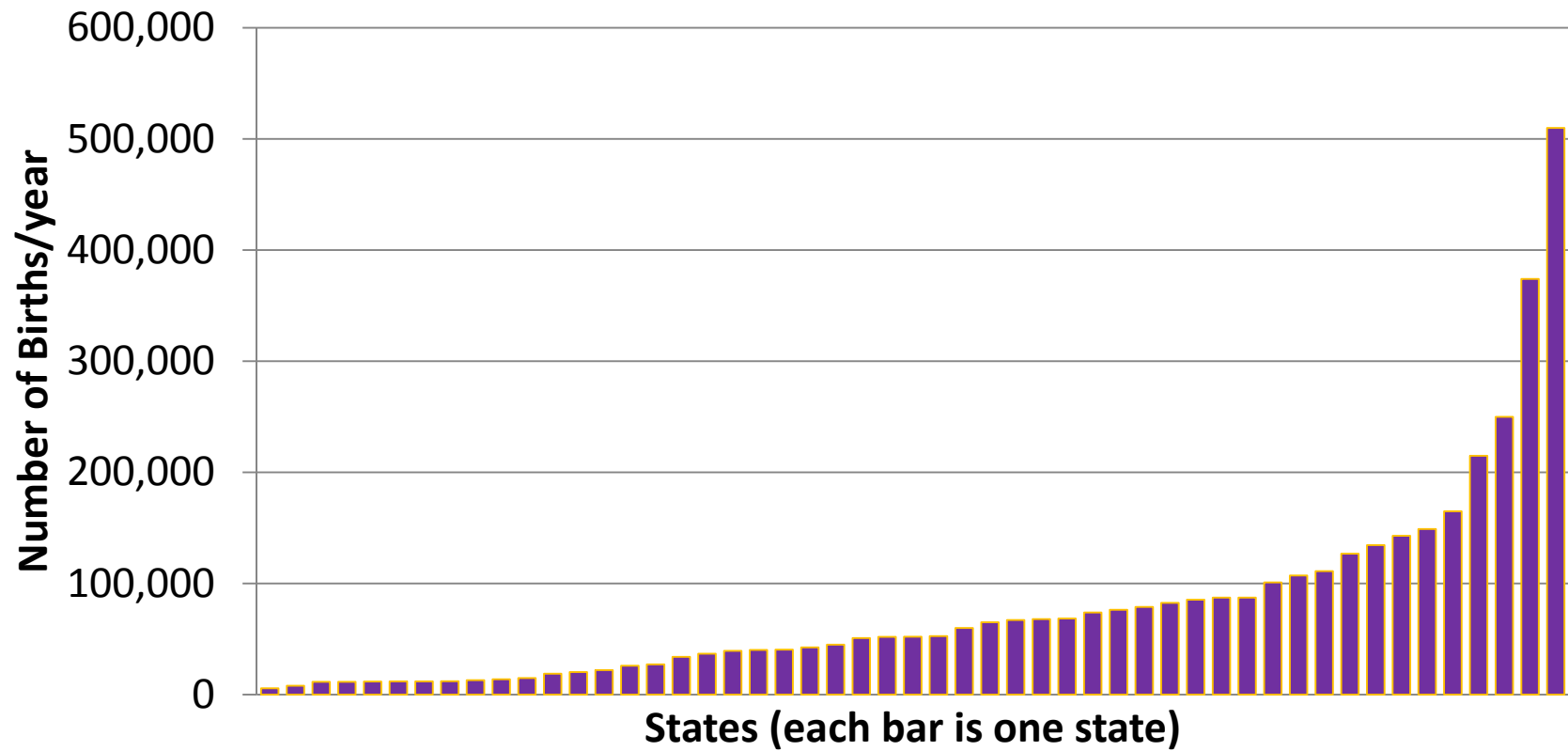


What do we know about our newborn screening systems in the U.S.?

- 51 newborn screening programs
- 36 newborn screening labs
- Geographically diverse
 - 663,000 Square Miles to 1,212 square miles



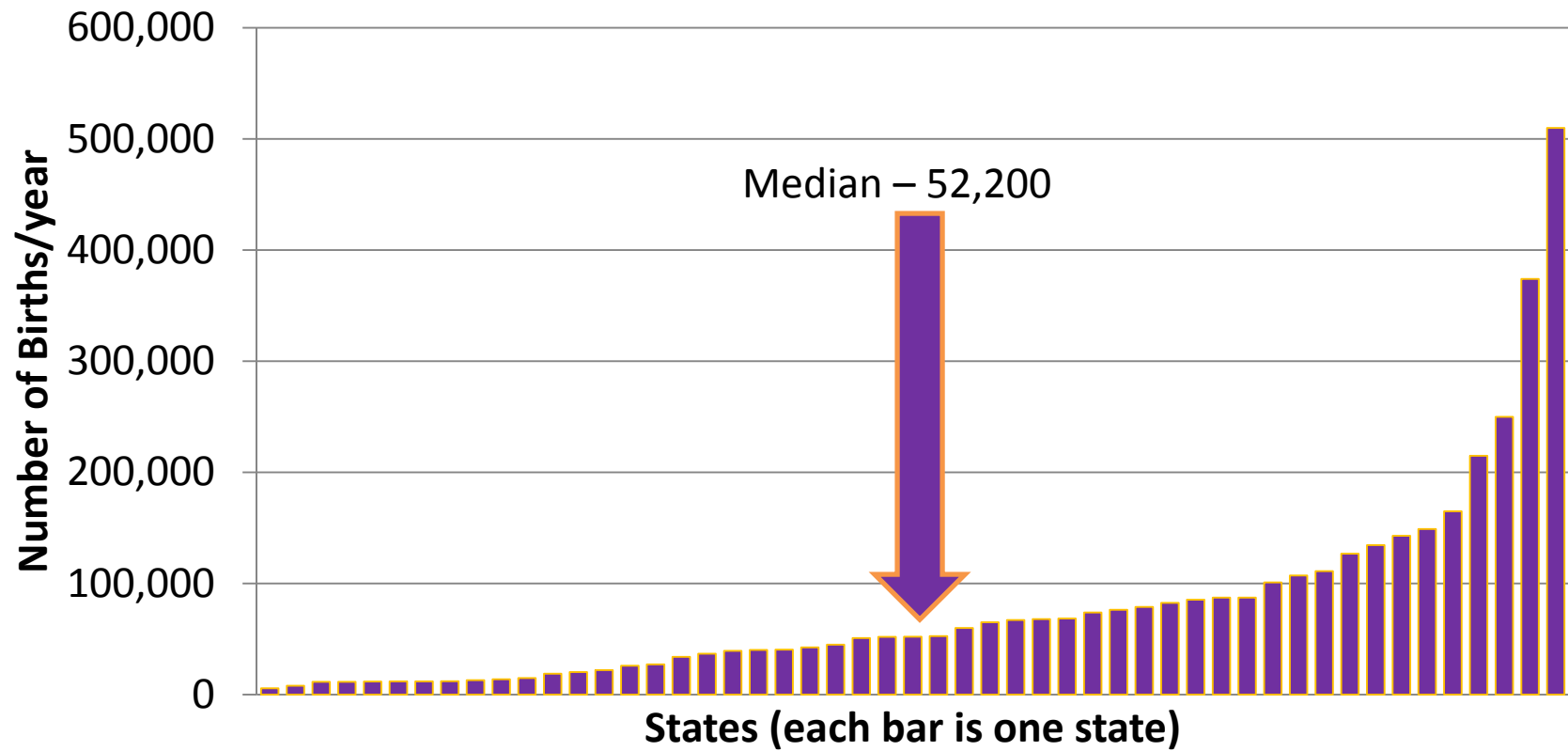
Number of Annual Births in the U.S.



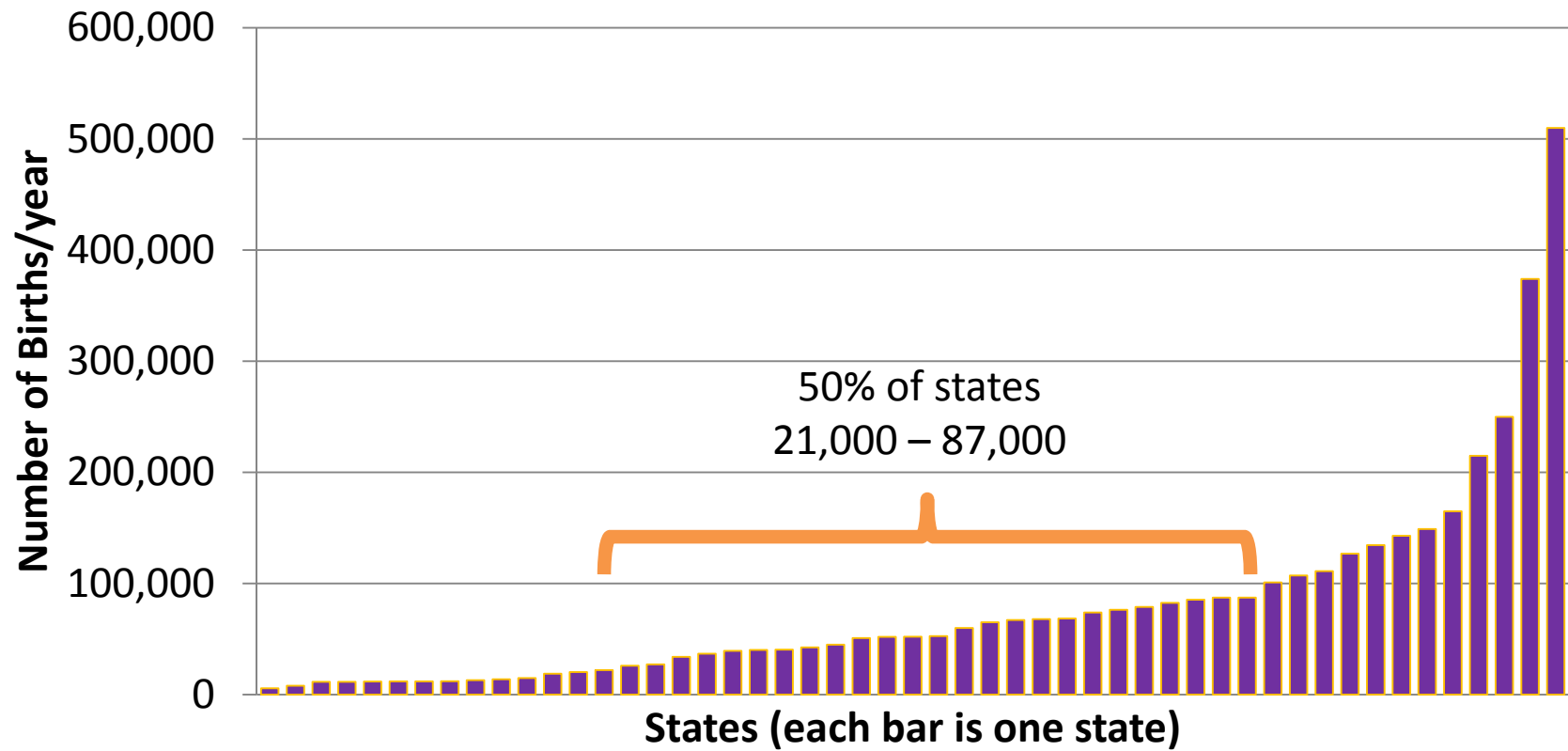
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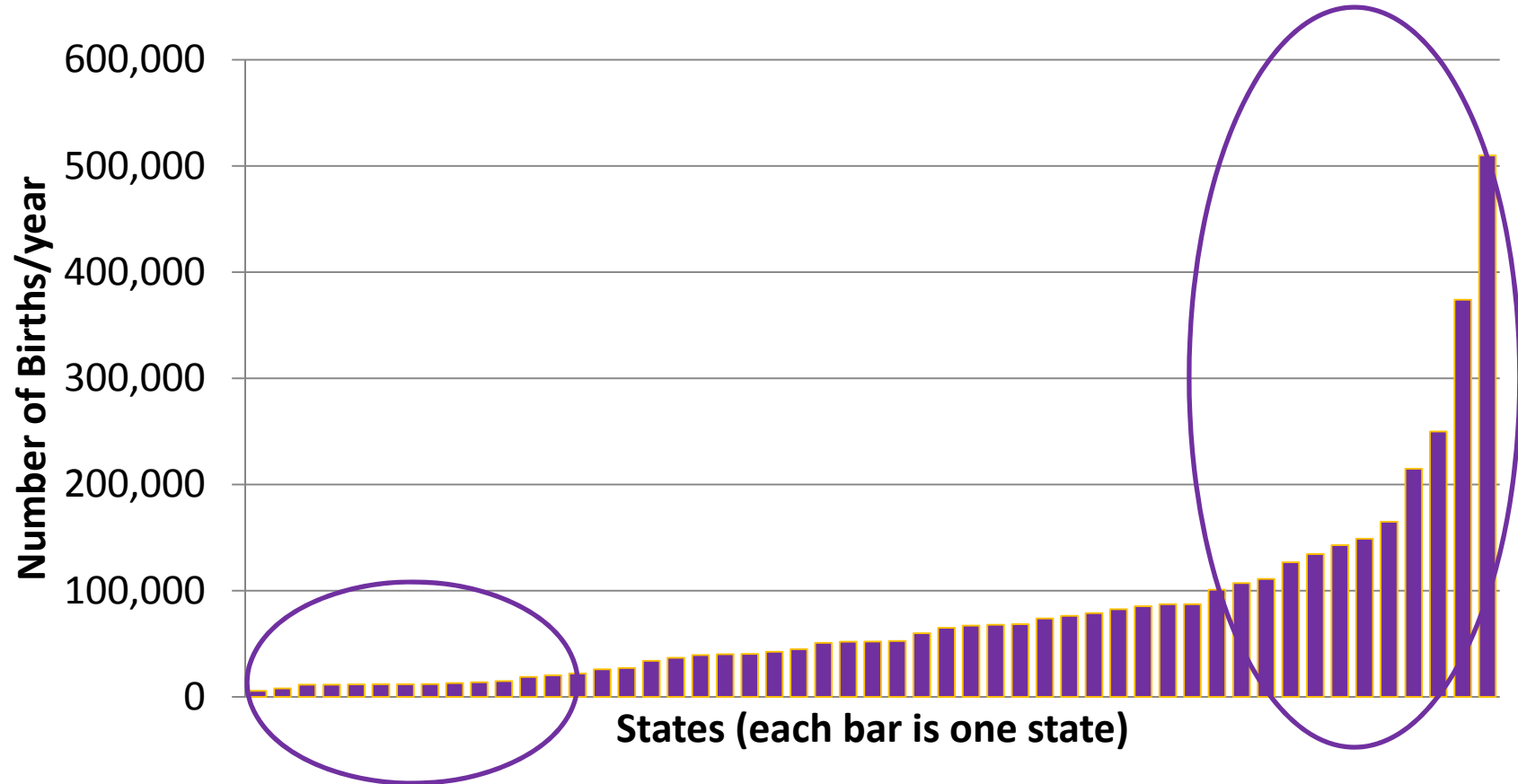
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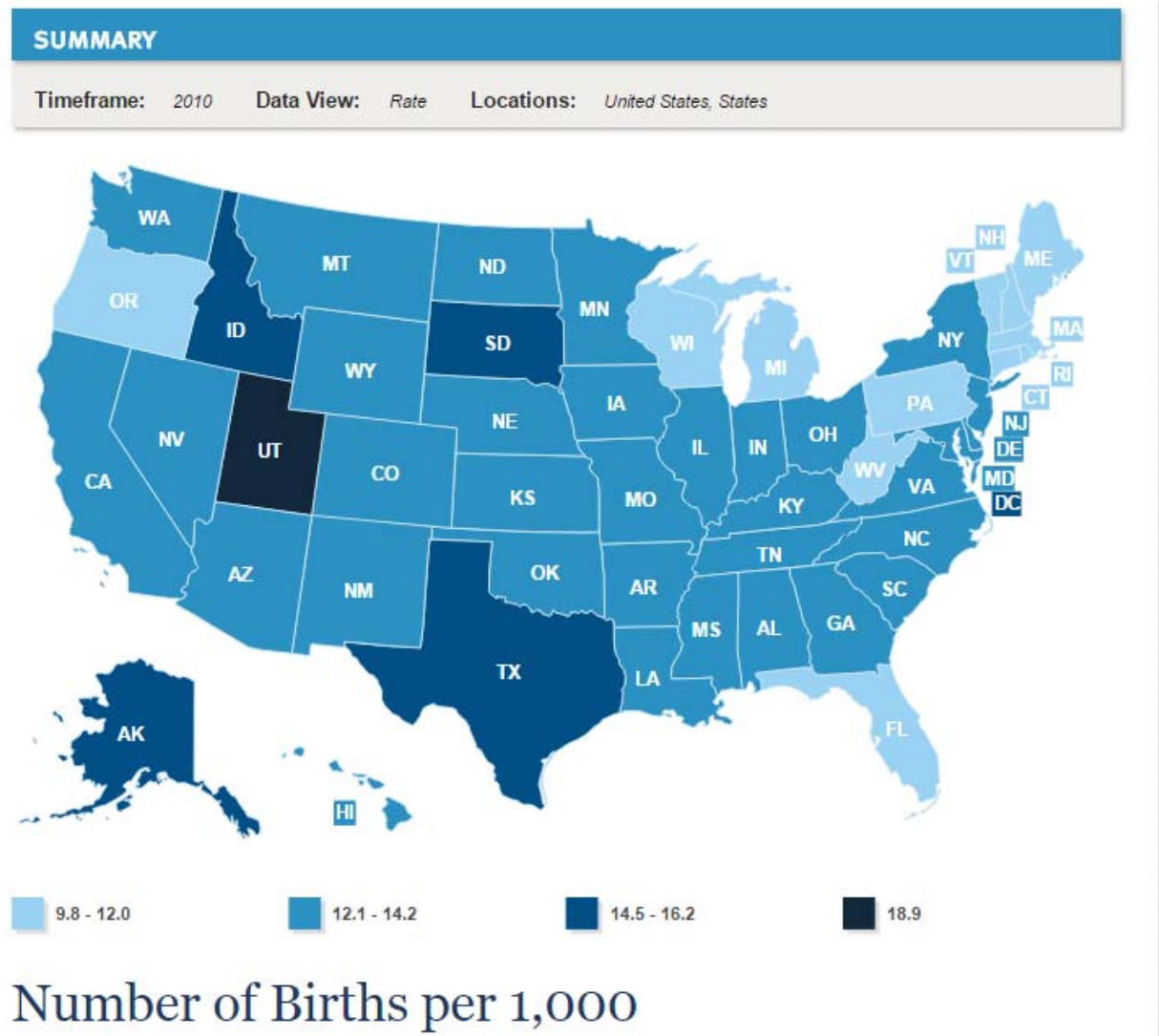
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Number of Annual Births in the U.S.



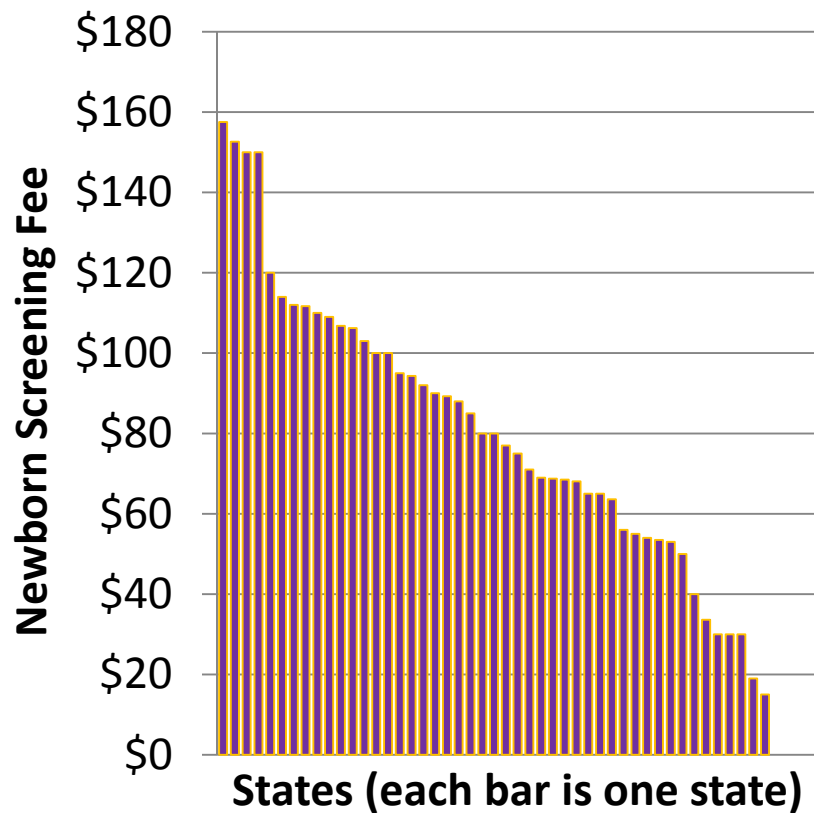
Birth rates vary between states

- The number of live births per 1,000 population varies
- May point to different needs



<http://kff.org/other/state-indicator/birth-rate-per-1000/#map>

NBS Fees in the United States

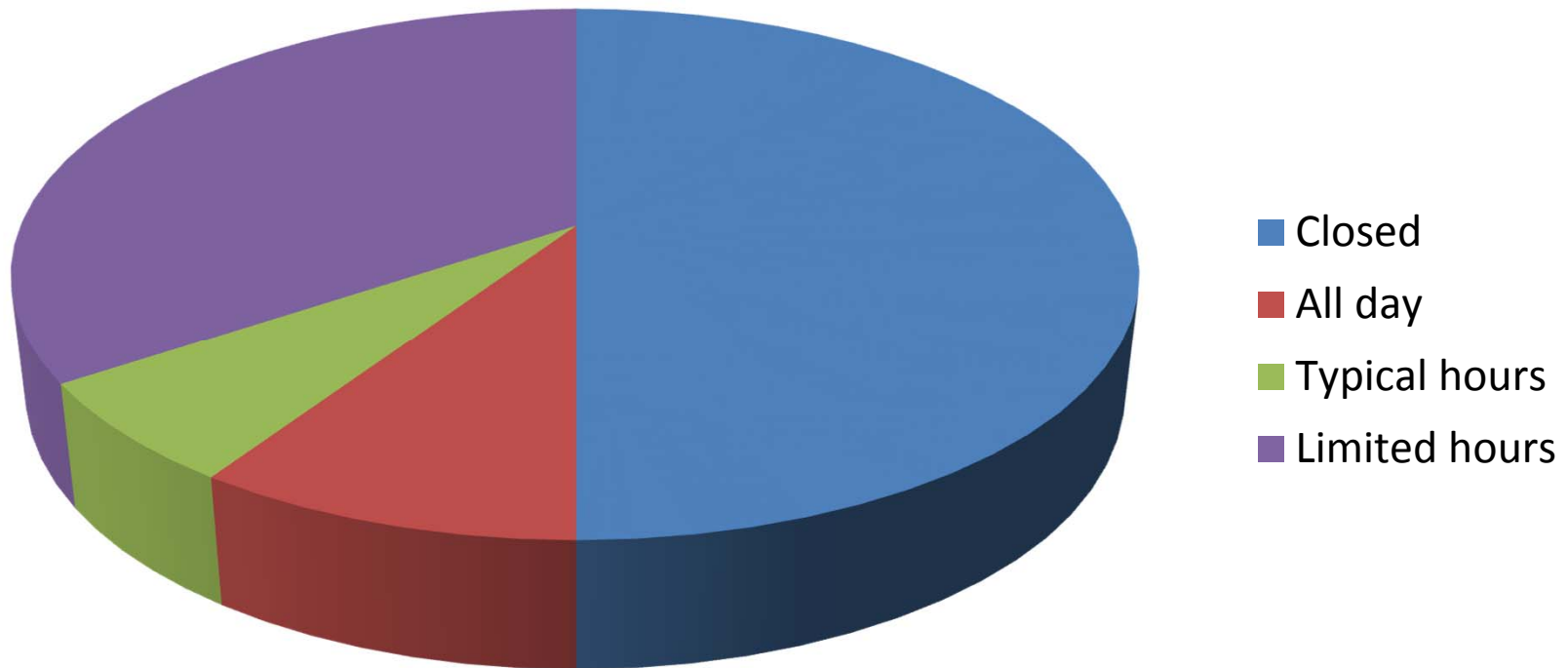


median	\$75.00
25th percentile	\$53.25
75th percentile	\$101.50

- In some states newborn screening fees are only a part of the funding source.
- How are fees used?
 - Lab tests
 - Follow-up
 - Clinical contractors
 - IT services
 - Courier Services
 - Administration
 - Education

Operating hours on Saturdays

Saturday Hours



N = 32



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Storage of Dried Blood Spots



- Storage of dried blood spots varies in state newborn screening programs
 - Recent legal events have changed the landscape
 - Changes are continuing



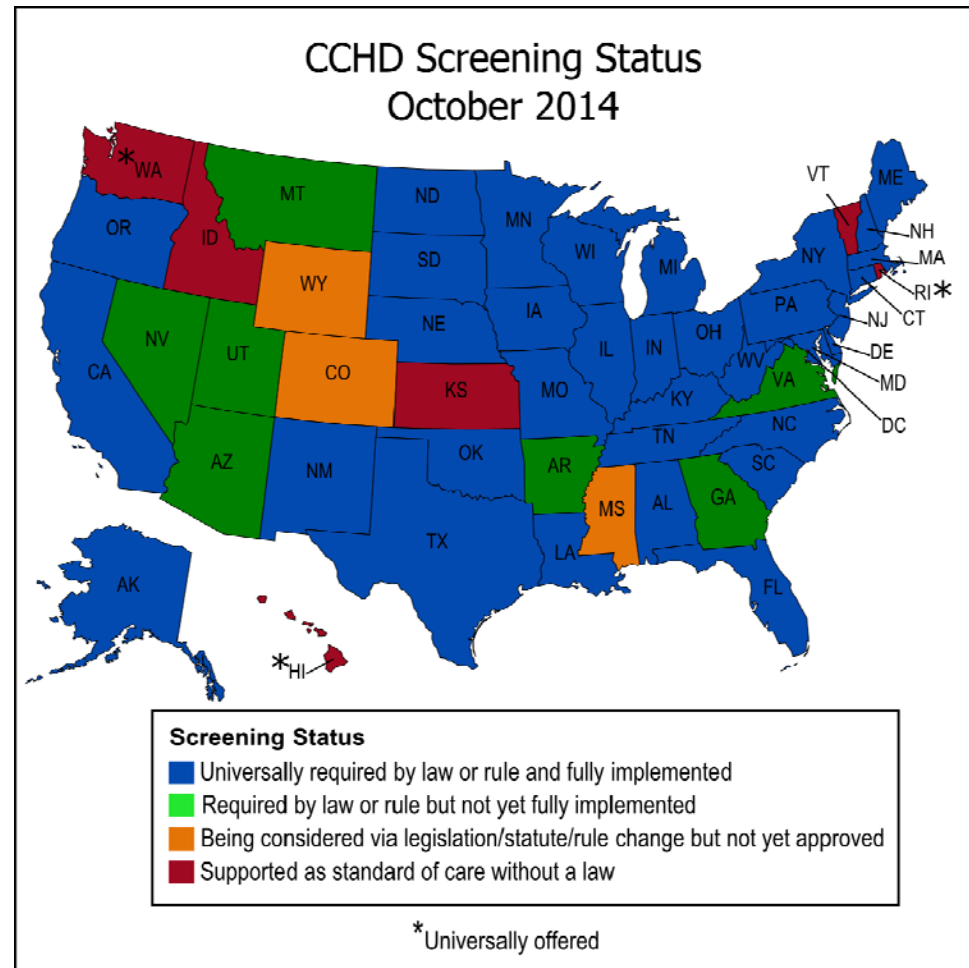
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Adding new disorders

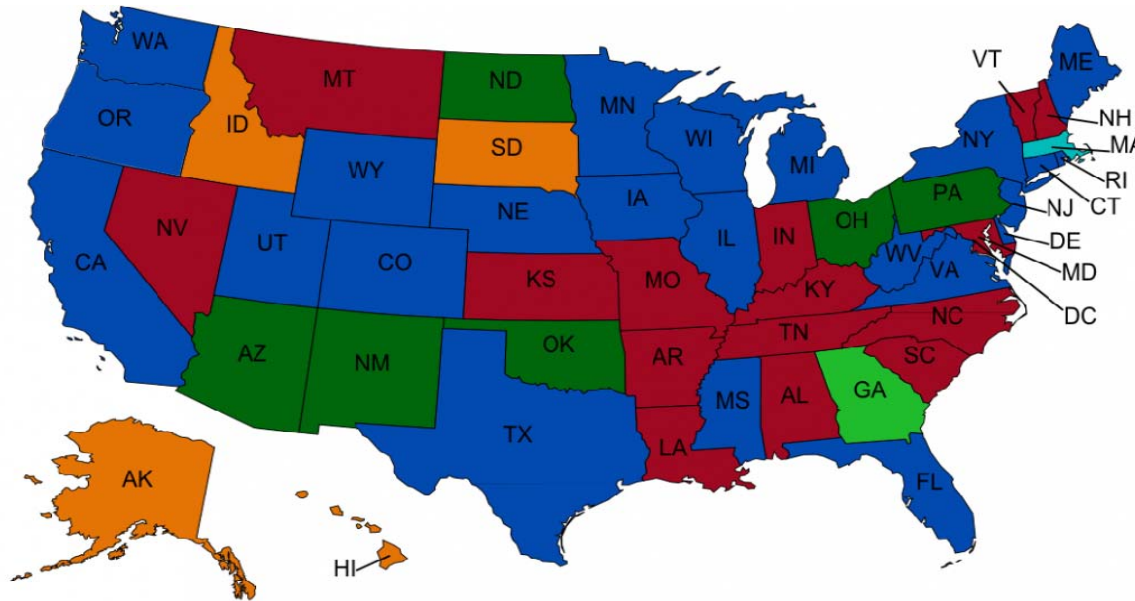
- Requirements for adding conditions vary by state
 - Legislative action
 - Board of Health/Advisory Committee
- Many states are faced with new screens added through legislative actions







Over 90% of infants are born in states with CCHD Screening Mandates



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Over 65% of infants in the U.S. are born in states with SCID mandates



	Universally Required by law/rule and fully implemented	60%
	Universally offered	2%
	Required but not yet implemented	4%
	Offered to select populations or by request	12%
	Being considered, not yet approved	1%
	Not screened	21%

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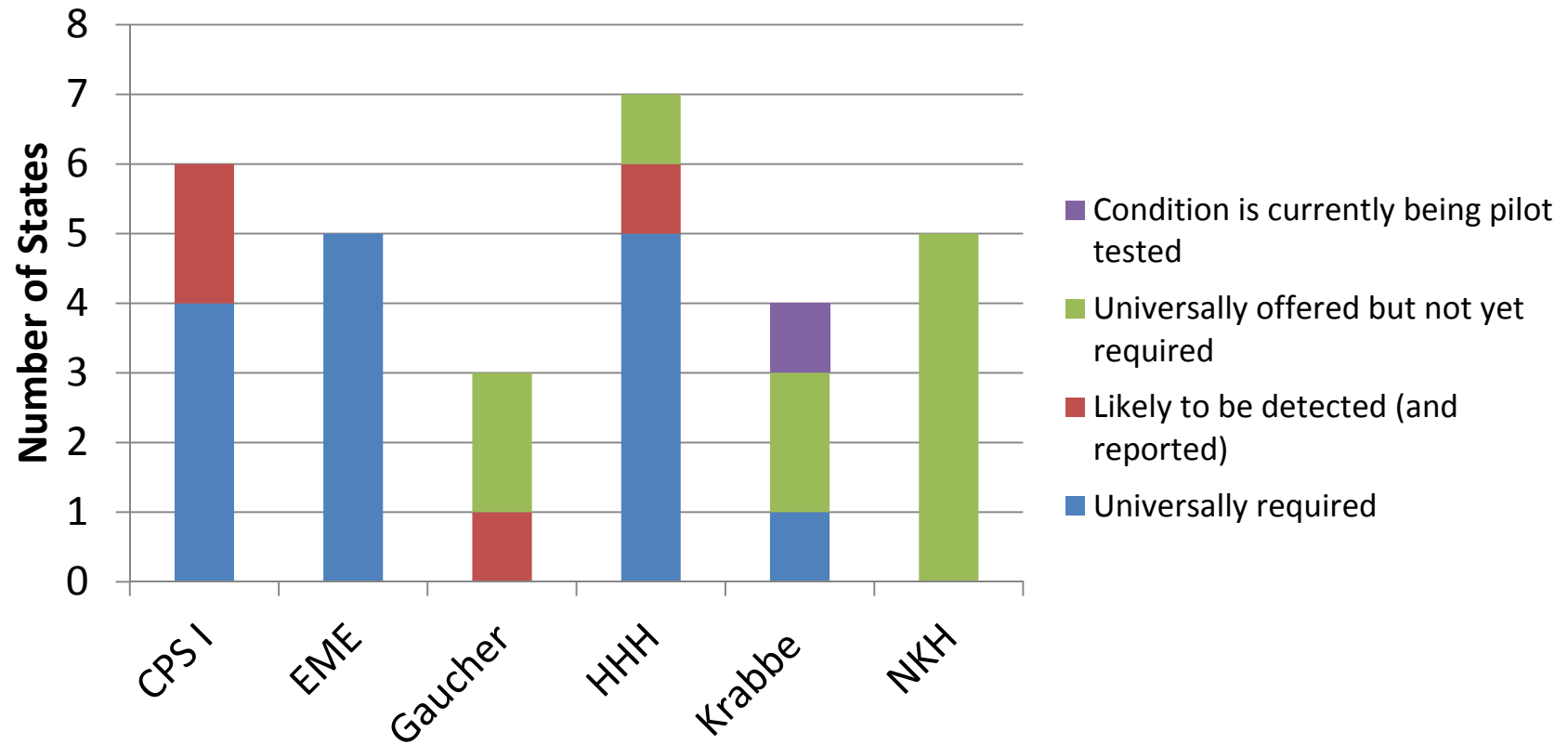
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New Conditions Under Consideration

- Decision pending from Secretary of Health Human Services for Pompe
 - Screened in 7 states (under mandates, pilots)
- Secretary's Discretionary Advisory Committee for Heritable Disorders in Newborns and Children Currently Reviewing:
 - Mucopolysaccharidosis I (MPS-1)
 - Screened/pilots in 4 states
 - X-linked Adrenoleukodystrophy (ALD)
 - Screened/pilots in 6 states

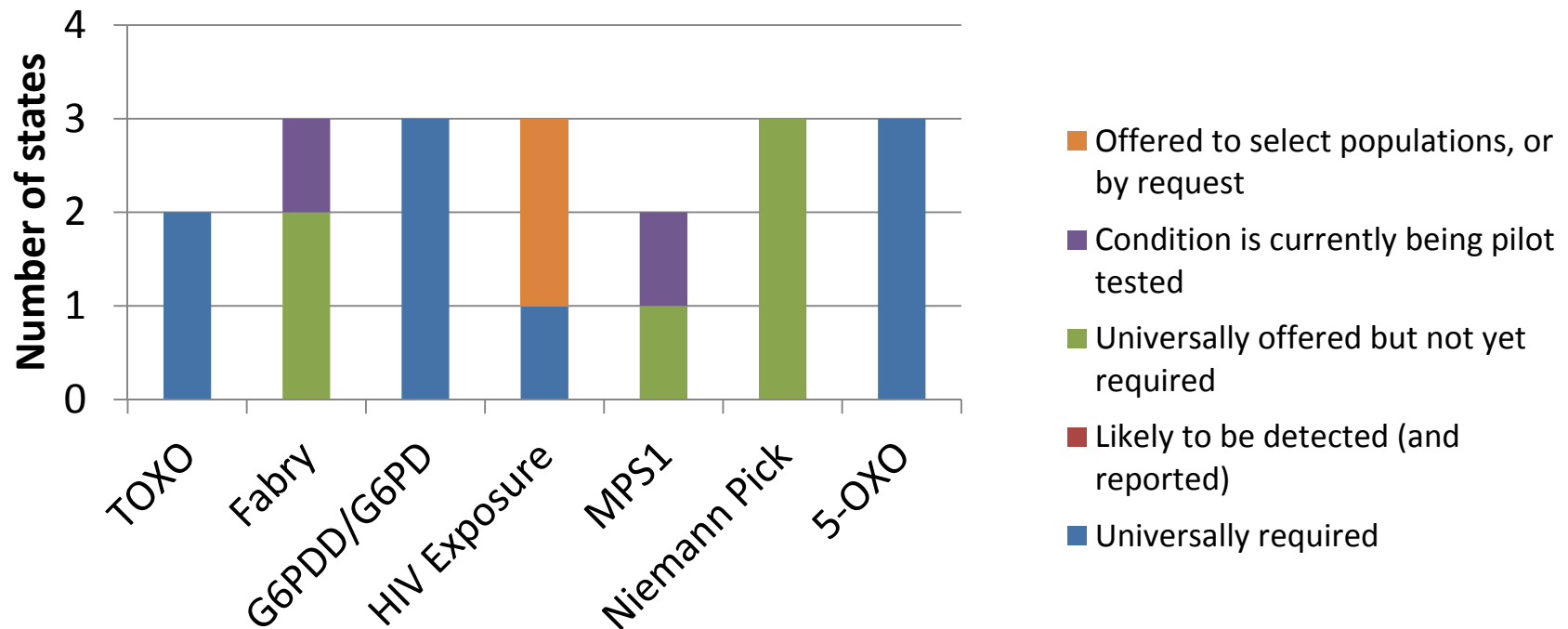
Screened Conditions Not on the Recommended Uniform Screening Panel



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Screened Conditions Not on the Recommended Uniform Screening Panel



Screened/Pilots in only one program

- Formiminoglutamic acidemia - FIGLU
- Hyperornithinemia with Gyrate Deficiency - Hyper ORN
- Mucopolysaccharidosis II - MPS II
- Prolinemia Type I/ Type II - PRO



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Making improvements in NBS



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March Of Dimes Honors Arizona With First-Ever Newborn Screening Award

Arizona Health Director Honored for Reforms to Avoid Deadly Delays

CHANDLER, ARIZONA — Thursday, September 18, 2014

Arizona turned its newborn screening program into a model other states can follow in just a few short months, earning it the first-ever Newborn Screening Quality Award from the March of Dimes.

The March of Dimes presented Will Humble, M.P.H., Arizona's Department of Health Services director, with the award at a ceremony held here today. Mr. Humble established a policy of full transparency for the length of time it takes Arizona hospitals to send newborn blood samples to the lab for analysis, and set a target of having 95 percent of samples screened within 72 hours.

"When hospitals hold onto blood samples for a few days, or a lab is closed on the weekend, this can lead to deadly delays for newborns," said Edward McCabe, MD, March of Dimes chief medical officer, who presented Mr. Humble the award today. "But under Will Humble's leadership, Arizona has put in place a process that is a model for other states to follow."

The March of Dimes established the new awards in honor of Dr. Robert Guthrie, known as "the father of newborn screening" for developing the first mass screening test for babies 51 years ago. The awards recognize leadership in establishing culture of safety as a way to avoid those deadly delays in states' newborn screening process. A Milwaukee Journal Sentinel investigative series highlighted the problem by telling the personal stories of babies who developed intellectual delays when their blood samples were not timely analyzed.

"Our goal is to save lives and prevent devastating disabilities for babies, and the cooperation and quick work of Arizona's hospital officials and our state Department

Trending

- f Anne Geddes Unveils New Image Of A Baby Born Too Soon
- f Caffeine in pregnancy
- f Thrombophillias
- f 39 Weeks
- f Vaccinations during pregnancy

World Prematurity Day
is November 17



Photo by Anne Geddes ©

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Colorado

Partnering with Colorado Hospital Association, laboratory and nursing staff:
“NBS process improvement group”

Mapped out processes of from prenatal care to follow-up

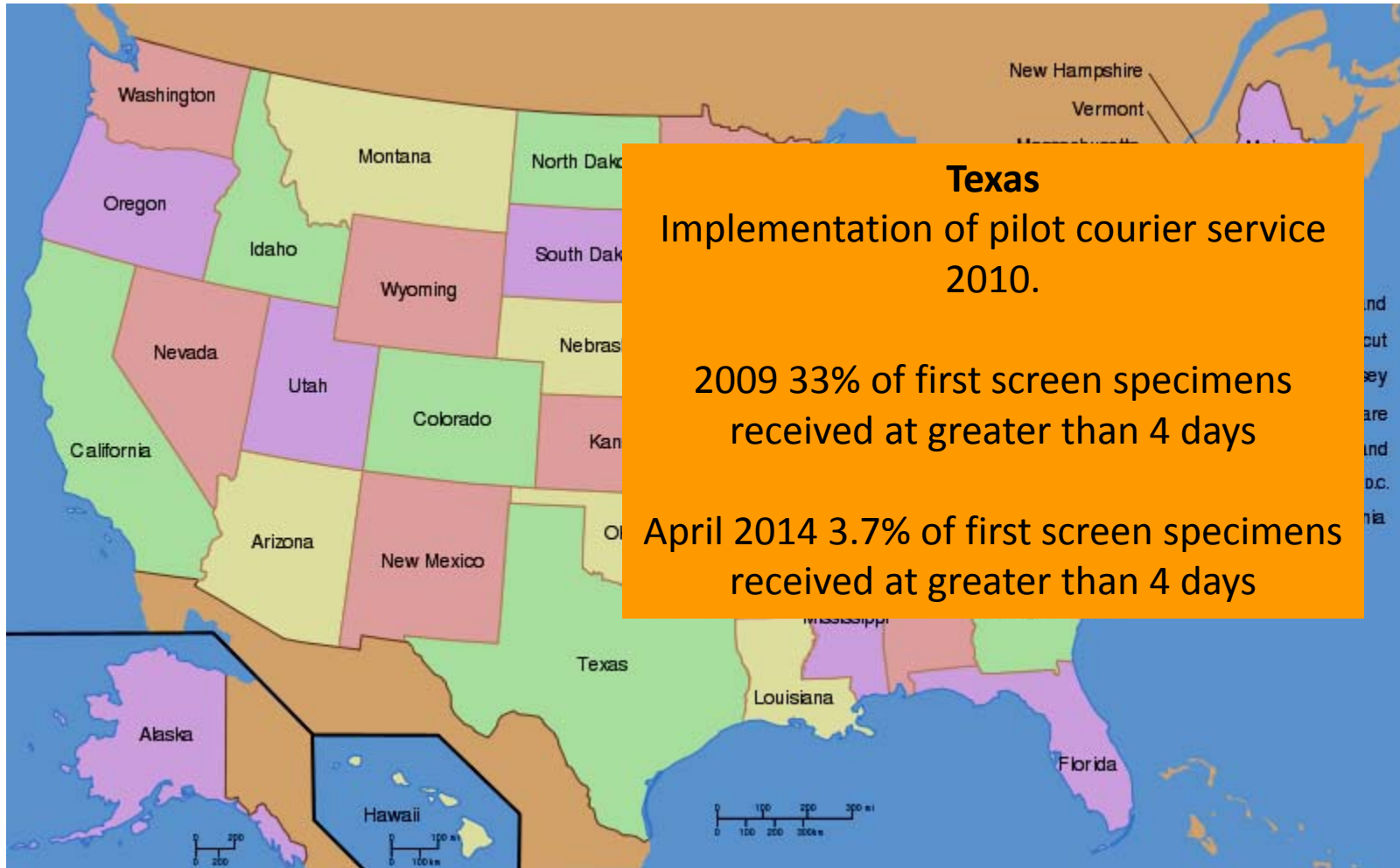
Implementing best practices



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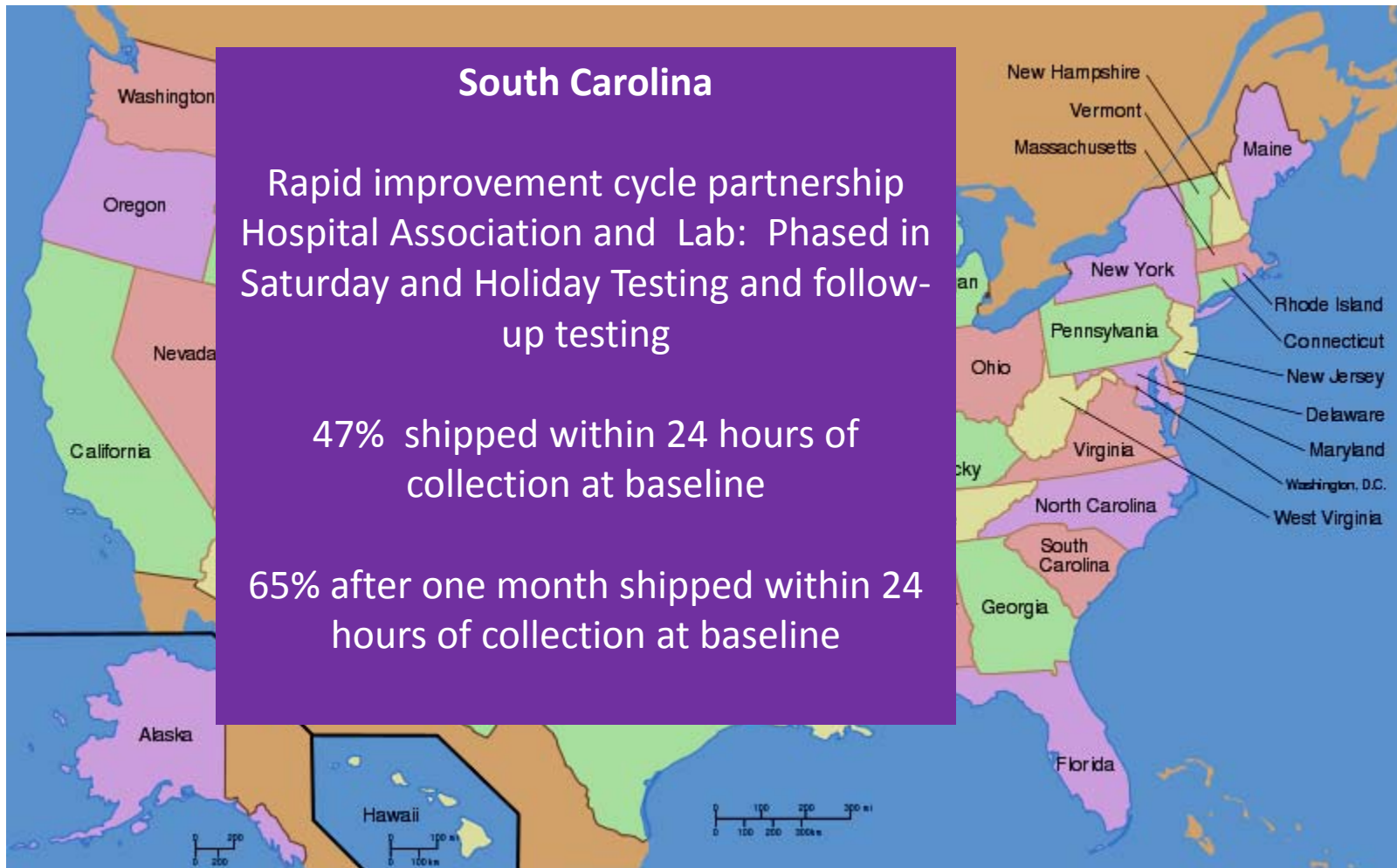
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Timeliness



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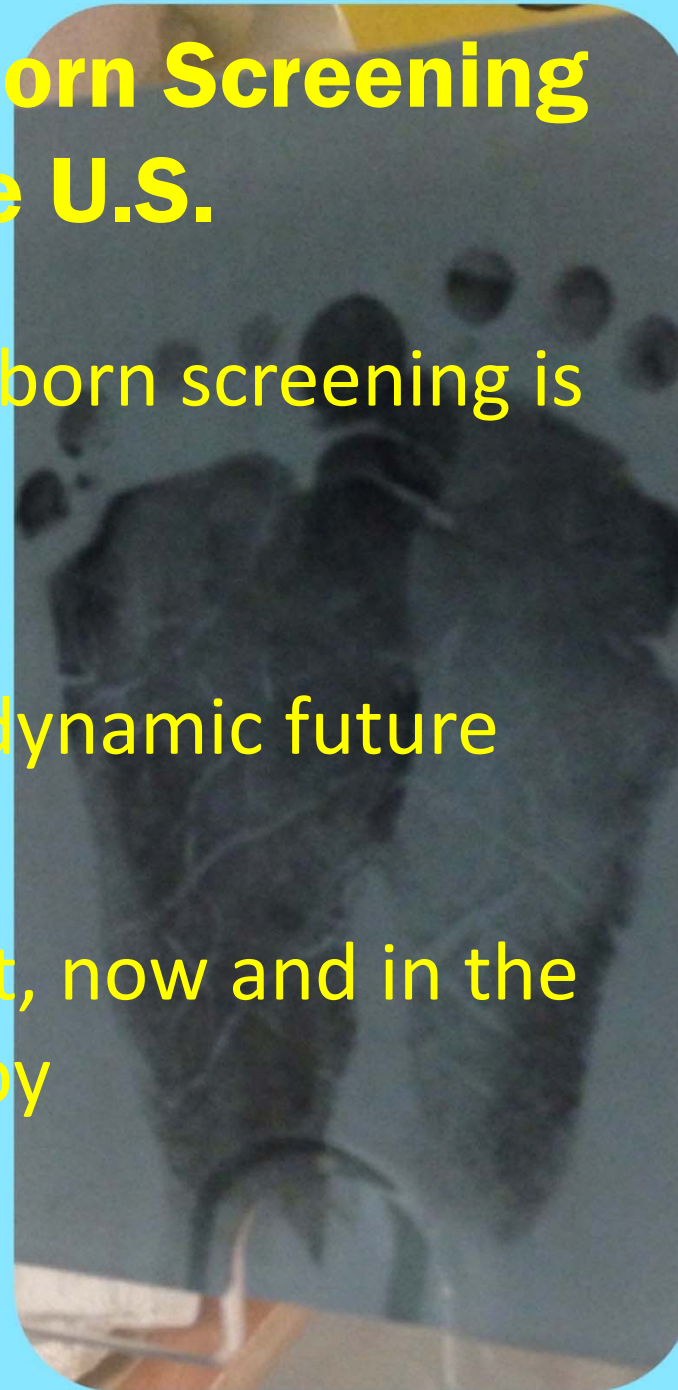


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State of Newborn Screening in the U.S.

- The state of newborn screening is strong
- We are facing a dynamic future
- The one constant, now and in the future, is the baby



Acknowledgments

- U.S. NBS Programs
- NBS Community
- NewSTEPs Committees

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