



NewSTEPS

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THE STATE OF THE NEWBORN SCREENING SYSTEM IN THE MOUNTAIN STATES REGIONAL GENETICS NETWORK

2022

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ASSOCIATION OF PUBLIC HEALTH LABORATORIES

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Vision

Dynamic newborn screening systems have access to and utilize accurate, relevant information to achieve and maintain excellence through continuous quality improvement.

Mission

To achieve the highest quality for newborn screening systems by providing relevant, accurate tools and resources and to facilitate collaboration between state programs and other newborn screening partners.



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COMMUNICATION & OUTREACH

Strengthening the newborn screening system through:

- ✓ Enhancement of the existing network of stakeholders by creating a **culture of trust**,
- ✓ providing opportunities for **timely & interactive communication**, and
- ✓ offering a **forum for collaboration** among national, regional and state NBS programs.



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TECHNICAL ASSISTANCE

Create dynamic national NBS TA resource center that proactively:

- ✓ Provides training,
- ✓ addresses challenges, and
- ✓ supports program improvement



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NEW DISORDER IMPLEMENTATION: Funding, Technical Assistance, Education

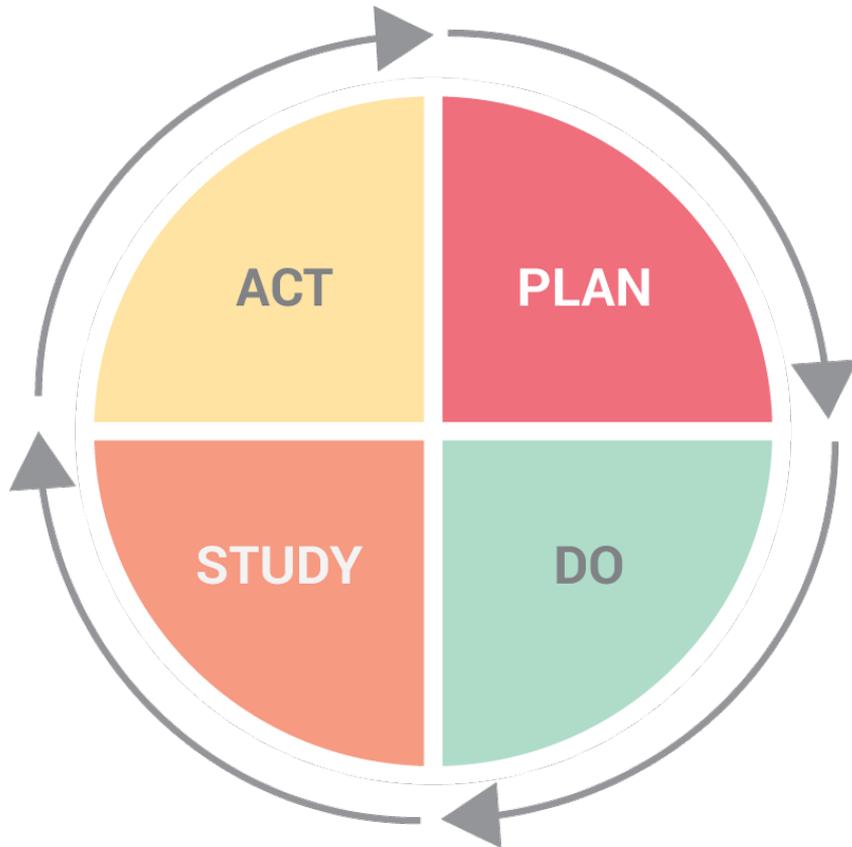
- ✓ Pompe
- ✓ MPS I
- ✓ X-ALD
- ✓ SMA



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CONTINUOUS QUALITY IMPROVEMENT (CQI)



Create a national program to facilitate CQI within the newborn screening system to support:

- ✓ Improvements to **detection of out-of-range results**
- ✓ Improvements to **communication of results**
- ✓ Improvements to **confirmation of diagnosis**
- ✓ Improvements to **timeliness activities**
- ✓ Address **emerging issues** in newborn screening (i.e., Continuity of Operations Planning during a global pandemic)
- ✓ Facilitate **collaboration, quality improvement processes** and **data collection and analysis** to track progress



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DATA

Continuous quality improvement and data-driven outcome assessments in the NBS system by providing:

- ✓ Standardized data repository,
- ✓ dynamic data infographics and visualization tools, and by
- ✓ supporting integration of health information technology



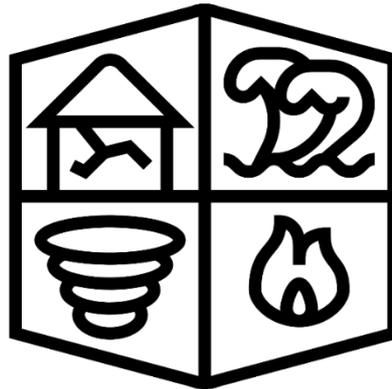
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2022



**Unprecedented
global pandemic?**



**Disruptive natural
disasters?**



**Babies being born
everywhere, every day?**



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Births in 2021

Year	National Births (50 states, DC, PR, Guam)	Mountain State Births	Percent of national births represented by Mountain States
2021	3,686,219	632,849	17%



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Mountain States Regional Genetics Network Newborn Screening Programs

8 NBS programs

- Arizona, Colorado, Montana, Nevada, New Mexico, Texas, Utah, Wyoming
- Regional labs serve **3** of the MSRGN states
- Each state has its own follow-up program
- NBS populations served between **6,230** births per year to **373,340** births per year in 2021
- **7** of these programs require 2 screens

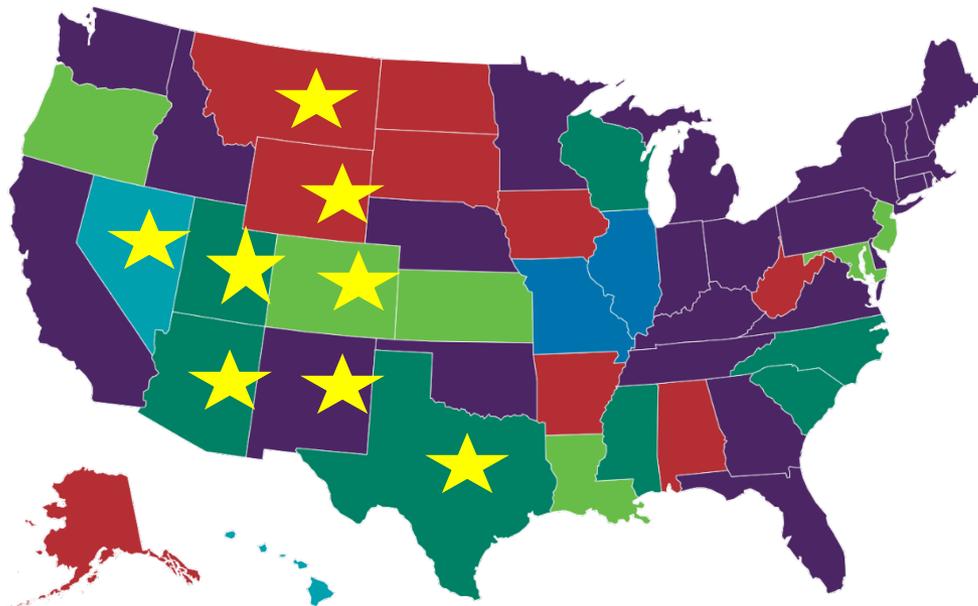


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CORE RUSP DISORDERS

October 2022



GU PR DC

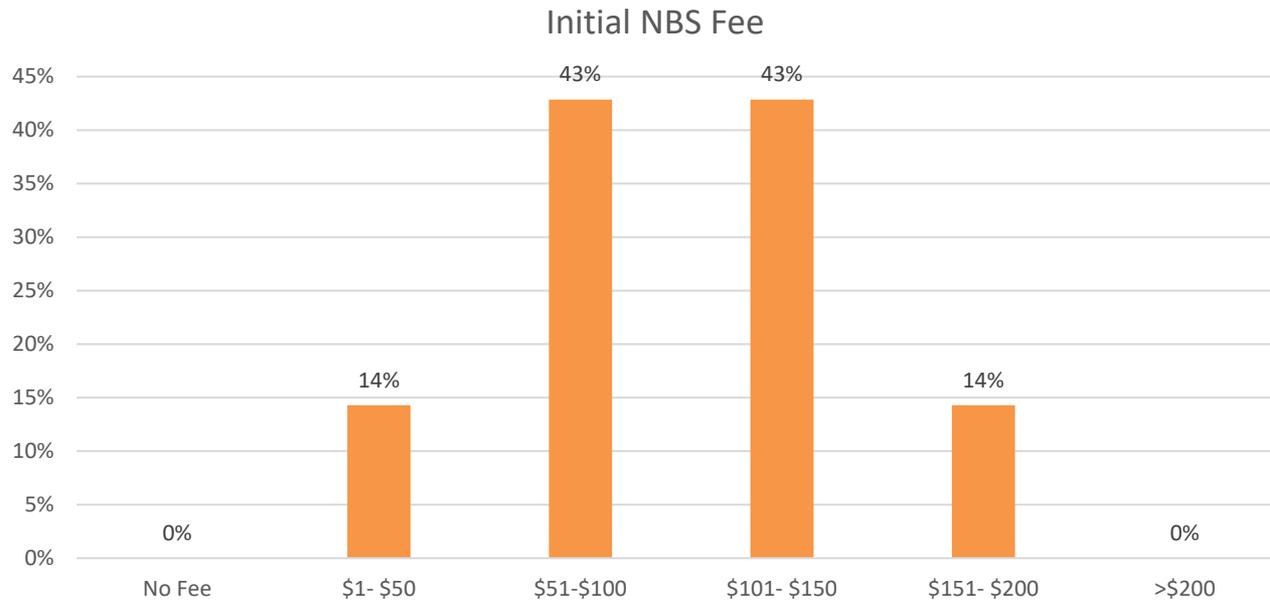
CORE RUSP Disorders Screened	Number of States	Mountain States
31	4	NV
32	9	MT, WY
33	7	AZ, TX, UT
34	7	CO
35	24	NM
36	2	-



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Newborn Screening Fees



State	First Screen NBS Fee	Second Screen NBS Fee
Arizona	\$36	\$65
Texas	\$63.55	\$63.55
Nevada	\$81	Included in initial fee
Wyoming	\$84	Included in initial fee
Colorado	\$111	Included in initial fee
Utah	\$125	Included in initial fee
Montana	\$134	
New Mexico	\$190	Included in initial fee



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Operating Hours

	Days per Week that Laboratory is Open	Days per Week that Follow-Up is Open
Arizona	5	5
Colorado	6	7
Montana	6	5
Nevada	5	5
New Mexico	5	7
Texas	6	6
Utah	7	7
Wyoming	6	5



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New RUSP Disorder Implementation

	Pompe (2015)	MPS I (2016)	X-ALD (2016)	SMA (2018)	MPS II (2022)
Mountain States Screening (as of Oct 2022)	2	2	4	7	0
Mountain States Region Newborns with Access to Universal Screening	13%	13%	89%	95%	0%



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Resources, Data Utility

- Inferences, correlations (if they exist)
- Data driven assessments
- Data driven quality improvement
- Equity analyses (ongoing)
- Timeliness analysis

Available by contacting newsteps@aphl.org



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Despite the challenges and stresses to the public health system in 2021-2022, the Newborn Screening system continues to:

- ✓ Add disorders to their screening panels
- ✓ Maintain quality practices
- ✓ Engage in continuous quality improvement (CQI) projects
- ✓ Uphold accreditations/certifications
- ✓ Perform collection, screening, analysis, reporting and follow-up in a timely fashion
- ✓ Address instrument failures, calibration needs, power outages, staff shortages, etc.
- ✓ Save babies!

THANK YOU

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SOURCES/REFERENCES:

www.newsteps.org