

# NewSTEPS Update

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APHL is collaborating with the Colorado School of Public Health to implement NewSTEPS.

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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.**



## **The Newborn Screening Technical assistance and Evaluation Program**

Providing:

- quality improvement initiatives for newborn screening systems
- innovative data repository
- technical and educational resources for state newborn screening programs

[www.newsteps.org](http://www.newsteps.org)

[newsteps@aphl.org](mailto:newsteps@aphl.org)

# HRSA Funded Activities

- **NewSTEPs:** 2012- 2014; 2014-2017
- **CoIIN for Timeliness in NBS:** 2014-2016
- **SCID Implementation:** 2014-2016 (NCE: 2017)
- **NewSTEPs 360:** 2015-2018
- **New Conditions Implementation:** 2016-2018

# Technical Assistance: Webinars

- **Webinars**
  - Short Term Follow Up
  - Critical Congenital Heart Disease
  - Health Information Technology
  - Severe Combined Immunodeficiency (SCID)
  - New Disorders



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# Technical Assistance: Site Reviews

- Request Site Review
- Complete Pre-Review Forms
- Assemble Site Review Team
- Comprehensive 3-5 day Site Review
- Detailed Report with Recommendations Issued

# NewSTEPS Data Repository

- State Profiles
- Quality Indicators
- Case Definitions

# Memorandum of Understanding

- Between NewSTEPs/APHL and each state
- Language includes:
  - Data ownership
  - Data sharing
  - Data reporting
  - Security language
  - IRB and OHRP language

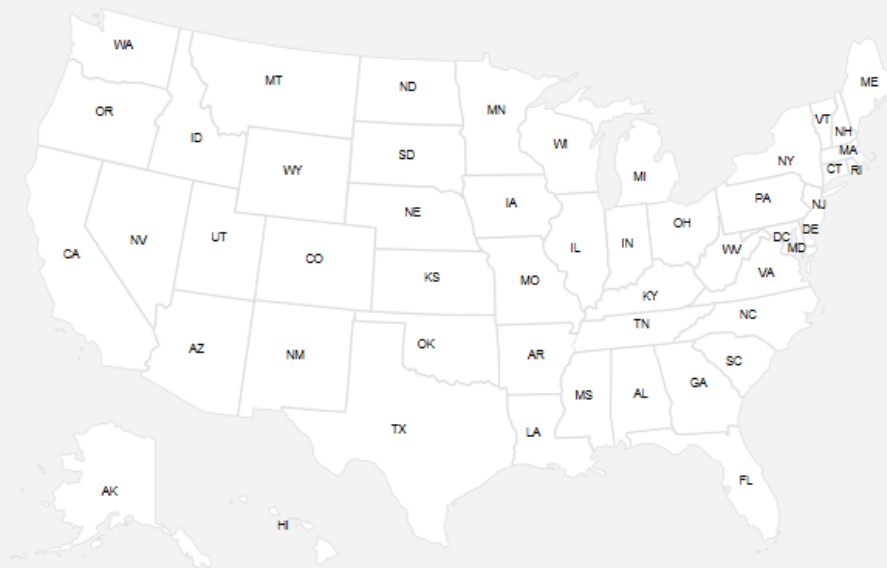


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# State Profiles

Select a state or click [here](#) to view aggregate reports.

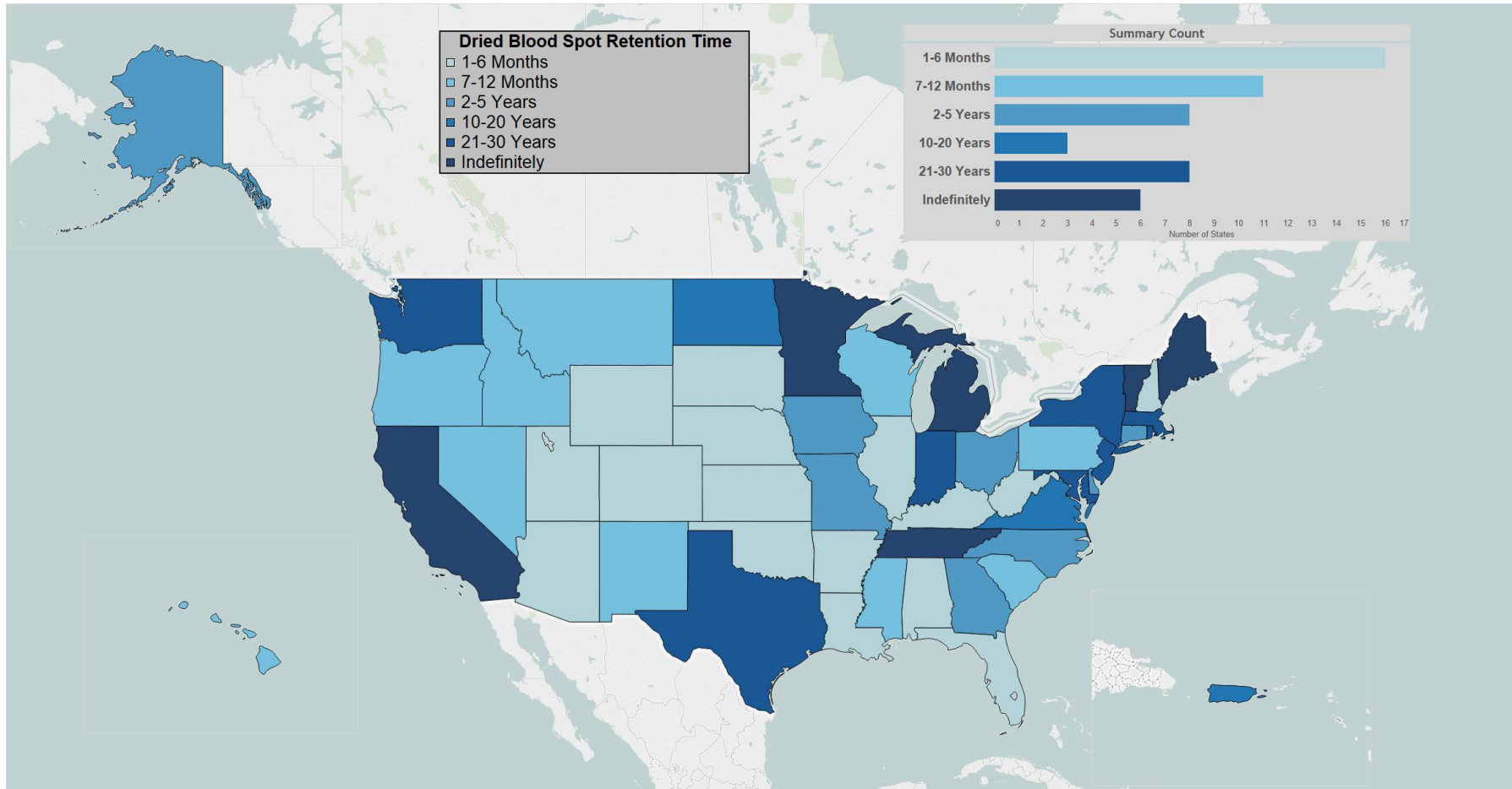


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# Dried Blood Spot Retention Time



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# How many NBS programs screen for...

## Screened Conditions Report

**Core** Secondary Other

Condition	Universally Required	Universally Offered	Offered Select	Considered	Req Not Implemented	Likely Detected	Pilot Tested
<b>Organic Acid Disorders</b>							
Propionic acidemia - PROP	52						
Methylmalonic acidemia (methylmalonyl-CoA mutase) - MUT	52						
Methylmalonic acidemia (cobalamin disorders) - Cbl A,B	51						
Isovaleric acidemia - IVA	52						
3-Methylcrotonyl-CoA carboxylase deficiency - 3-MCC	50					2	
3-Hydroxy-3-methylglutaric aciduria - HMG	52						
Holocarboxylase synthase deficiency - MCD	51					1	
Beta-Ketothiolase deficiency - BKT	52						
Glutaric acidemia type I - GA1	52						
<b>Fatty Acid Disorders</b>							
Carnitine uptake defect/carnitine transport defect - CUD	52						
Medium-chain acyl-CoA dehydrogenase deficiency - MCAD	52						
Very long-chain acyl-CoA dehydrogenase deficiency - VLCAD	52						
Long-chain L-3 hydroxyacyl-CoA dehydrogenase deficiency - LCHAD	52						
Trifunctional protein deficiency - TFP	51					1	

# How do NBS programs screen for...

## Conditions By Query Report

Type or select a condition name: \*

3-Methylcrotonyl-CoA carboxylase deficiency - 3-MCC

- First Screen First Tier Method

- First Screen First Tier Target

- Equipment -

Submit

State	Status	First Screen First Tier Method	First Screen First Tier Target	Equipment
Alabama	Universally required by Law or Rule and fully implemented			
Alaska	Universally required by Law or Rule and fully implemented	MS/MS non-derivatized	C5-OH	Waters Quattro Micro
Arizona	Universally required by Law or Rule and fully implemented			
Arkansas	Universally required by Law or Rule and fully implemented			
California	Universally required by Law or Rule and fully implemented			
Colorado	Universally required by Law or Rule and fully implemented	MS/MS non-derivatized	C5-OH	TQDs
Connecticut	Universally required by Law or Rule and fully implemented			
Delaware	Universally required by Law or Rule and fully implemented			



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# LIMS SYSTEMS

## Maps and Reports

- **Screened Conditions Report** - Report of screened condition counts
- **Conditions By Query Report** - Query for screened condition details
- **NBS Fees Report** - Provides information on the NBS fees each state NBS program is charging
- **DBS Retention Report** - Provides information on the dried blood spot specimen storage/retention times and storage conditions for each state NBS program
- **Courier System Report** - Provides information on the Courier system each state NBS program is using
- **LIMS System Report** - Provides information on the LIMS system each state NBS program is using
- **Data Retention Report** - Provides information on NBS data retention periods for each state NBS program



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# By the Numbers...

- **60%** of NBS programs have fully ratified MOUs or are close to ratifying
- **>300** registered NewSTEPs data repository users
- **>4,000** cases entered into the NewSTEPs data repository



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## Did you know...

*That the following real-time queries are now available on the [NewSTEPs website](#) to answer your questions about newborn screening programs?*

- [Screened Conditions Report](#) - the status of NBS conditions that are screened in each state.
- [Conditions By Query Report](#) - details (e.g., equipment used) on the screened NBS conditions.
- [NBS Fees Report](#) - the NBS fees charged by each state.
- [DBS Retention Report](#) - the dried blood spot (DBS) specimen storage /retention times and storage conditions for each state NBS program.
- [Courier System Report](#) - the courier system used by each state NBS program.



- Supports 24 state newborn screening programs to improve timeliness over three years
- Builds on success of COLIN
- Monthly calls with all states
- Continuous Quality Improvement coaches assigned to each state/group for monthly check in calls

NewSTEPS 360 and related activities are funded through a [cooperative agreement \(#UG8MC28554\)](#) to ColoradoSPH by the Genetic Services Branch of the Health Resources and Services Administration (HRSA).

# New Disorders RFP

- Funding for Peer Network Resource Centers and Newborn Screening programs
- Implement or provide TA and NBS for X-ALD, MPS-1 and/or Pompe newborn screening
- Timeline
  - Issued: October 11
  - TA Webinar: October 18
  - Letter of Intent: October 19
  - Application Due Date: **November 18**

[www.aphl.org/rfp](http://www.aphl.org/rfp)



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# Technical Assistance: Meetings & Workshops

- **Short Term Follow-Up** In-Person Meeting
  - October 25-26, 2016 | Orlando, FL
- **NewSTEPS 360** In-Person Meeting
  - November 16-17, 2016 | Bethesda, MD
- **Gene Sequencing in Public Health NBS** Meeting
  - February 16-17, 2017 | Atlanta, GA
- **New Conditions** In-Person Meeting: TBD
- **Tandem Mass Spectrometry Follow-Up** Workshop: TBD

# NewSTEPS Team



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