

NewSTEPS

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



NewSTEPS

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Cooperative Agreements

NewSTEPs

Communication | Data Repository | Technical Assistance

NewSTEPs 360

Timeliness | Continuous Quality Improvement

Severe Combined Immunodeficiency

Implementation | Education | Technical Assistance

New Disorders

Implementation | Education | Technical Assistance



NewSTEPs

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NewSTEPS Steering
Committee

Health Information
Technology Work Group

Critical Congenital Heart
Disease Work Group

Short Term Follow Up
Work Group

New Conditions
Work Group

Data Request Review
Subcommittee

Case Definitions
Work Group

Quality
Indicators
Work Group

Evaluation
Tool Work
Group

Data
Repository
Work Group

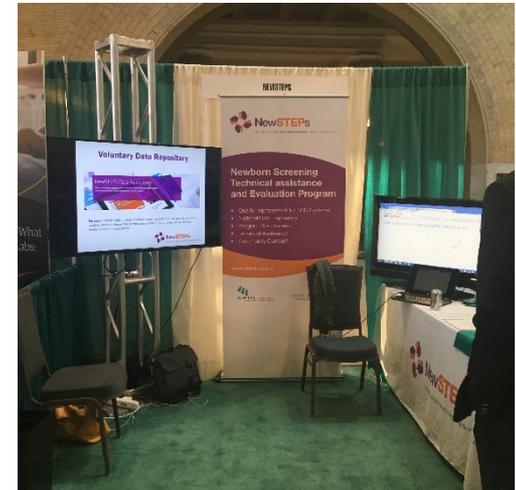
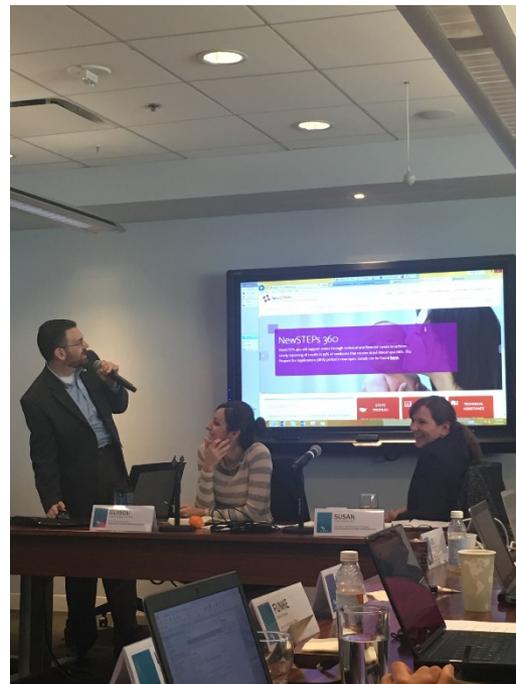
Website
Work Group



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Outreach & Relationship Building



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Communication



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.



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Disorder Specific Outreach

Disorder	# of National Webinars	All State In-Person Meeting	Funding to NBS Programs
CCHD	31	February 2014 Silver Spring, MD	
SCID	10	July 2015 Bethesda, MD	√
Pompe	2	Spring/Summer 2017 Washington DC	√
MPS-1			√
X-ALD			√
Cystic Fibrosis		June 2016 Denver, CO	√



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Health Information Technology

- National Webinars: 5
- **HIT Workgroup**
- HL7 Task Force



HL7 Implementation Guide for Newborn Screening Dried Blood Spot **Results Reporting**

HL7 Implementation Guide for **Ordering** Newborn Dried Blood Spot Newborn Screening



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Short Term Follow-Up

- National Webinars: 19
- **Short Term Follow-Up Workgroup**
- National In-Person Meeting | October 2016 in Orlando, FL.
- Position Paper



Tandem Mass Spectrometry Follow-Up Workshop

- 4 Workshops
- >40 participants
- Increasing demand

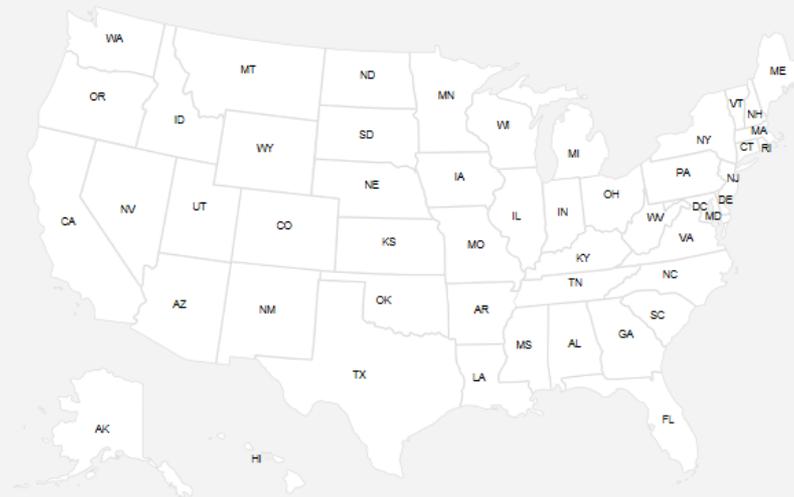


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State Profiles

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



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Quality Indicators

- Quality Indicator 1** Percent of dried blood spot specimens that were unacceptable due to improper collection and/or transport
- Quality Indicator 2** Percent of dried blood spot specimens with at least one missing state-defined essential data field upon receipt at the lab
- Quality Indicator 3** Percent of eligible newborns not receiving a newborn screen, reported by dried blood spot or point-of-care screen(s)
- Quality Indicator 4** Percent of infants that have no recorded final resolution (confirmed diagnosis or diagnosis ruled out by an appropriate medical professional) with the newborn screening program
- Quality Indicator 5** Timeliness of newborn screening activities
- Quality Indicator 6** Percent of infants with an out-of-range newborn screen result requiring clinical diagnostic workup reported by disorder category
- Quality Indicator 7** Percent of disorders detected by newborn screening with a confirmed diagnosis by an appropriate medical professional
- Quality Indicator 8** Percent of missed cases, reported by disorder



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Case Definitions

- >4,500 case definitions in NewSTEPS Data Repository
- 26 disorders
- Currently being developed: CCHD and SCID
- Future: Pompe, MPS-1, X-ALD



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- Builds on success of CoIN (8 states)
- Supports 28 state newborn screening programs to improve timeliness over three years
- 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).



Top Ten

- Engagement of STFU Community
- Expanding Funding → Expanding Impact
- >66% states have signed MOUs
- Outreach and Partnerships within the community and between federally funded partners
- Convening stakeholders in NBS, facilitating communication and information sharing
- Secure Data Repository



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

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