

NewSTEPs: Year One

Newborn Screening Technical assistance
and Evaluation Program

www.newsteps.org

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



NewSTEPS

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SOURCE: Association of Public Health Laboratories (APHL)



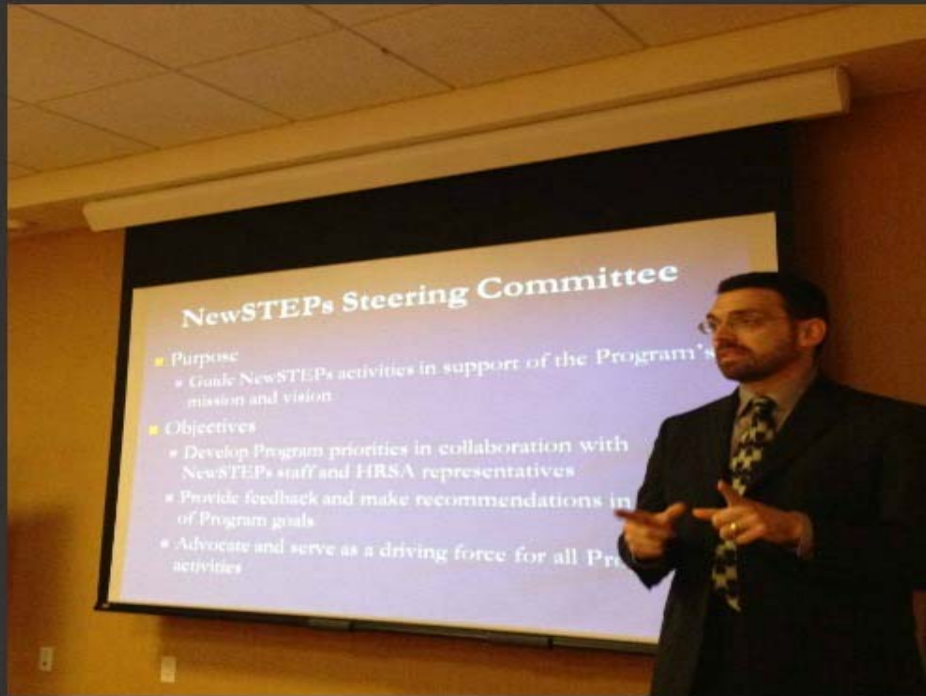
May 30, 2012 14:37 ET

APHL Awarded Multi-Million Dollar Cooperative Agreement for Newborn Screening Technical Assistance and Evaluation Program

SILVER SPRING, MD--(Marketwire - May 30, 2012) - The [Association of Public Health Laboratories \(APHL\)](#) has been awarded a five-year cooperative agreement of up to \$4.1 million by the Genetics Services Branch of the U.S. Health and Human Services Health Resources and Services Administration (HRSA) to develop and manage the Newborn Screening Technical Assistance and Evaluation Program (NewSTEPS). NewSTEPS will provide quality improvement initiatives for [newborn screening](#) systems, a new data repository, and technical and educational resources to state newborn screening programs and stakeholders.

For nearly 50 years, babies born in the United States have been routinely screened by the state





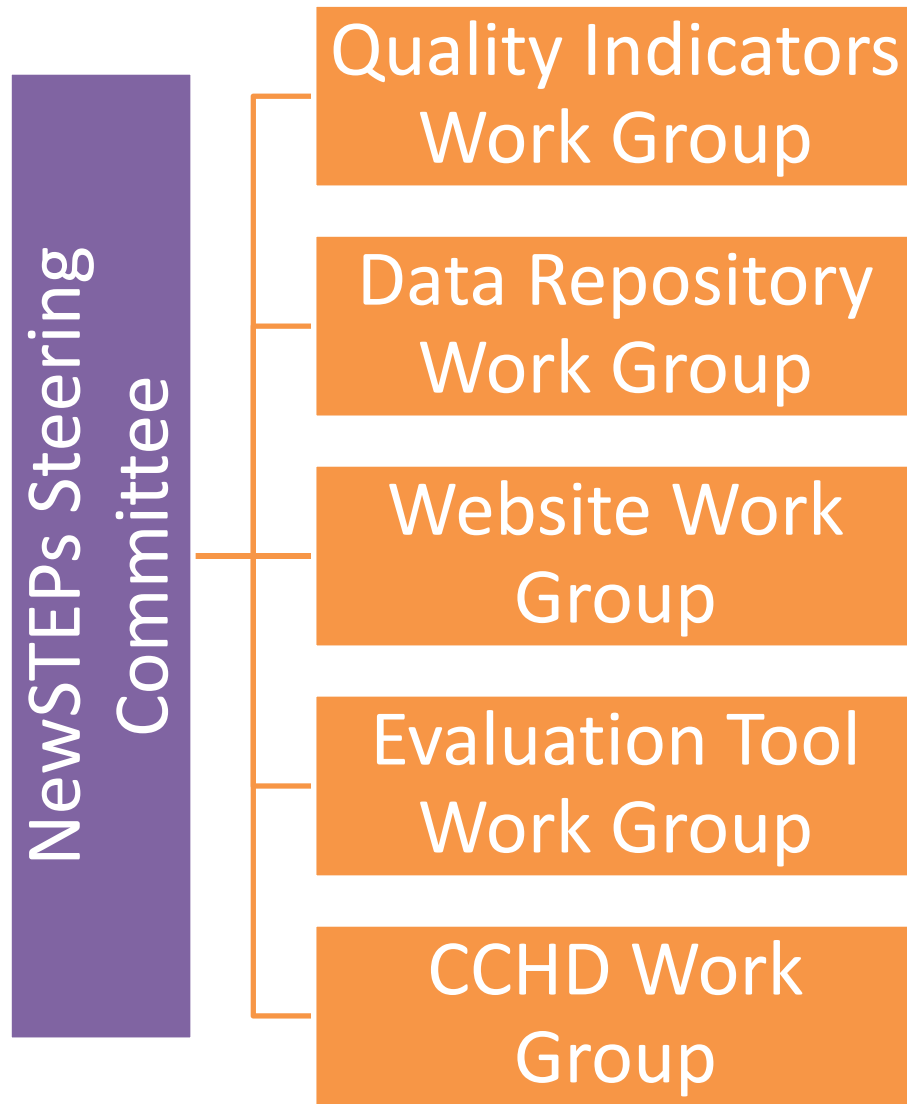
Vision

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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NewSTEPs Activities



NewSTEPs Accomplishments

- Relationship Building
- Program Evaluation and Community Input
- Evaluation Site Visits
- Development of Voluntary Data Repository
- Creation of Innovative Website
- Development of Quality Indicators
- NBS Surveillance Case Definitions Pilot Testing and Implementation
- Disease Specific Outreach
- Continuous Quality Improvement (CQI) Program



NewSTEPs
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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 newsteps@aphl.org

Relationship Building

Regional Collaboratives

National Meetings

Creating a National Presence

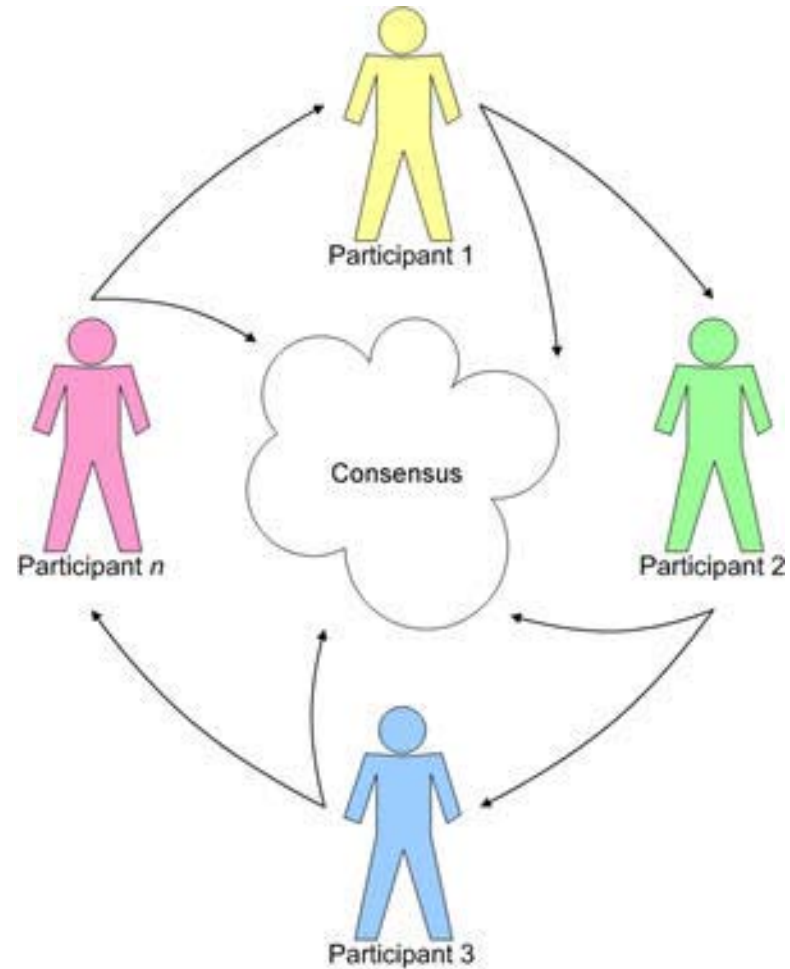


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Program Evaluation and Community Input

- NewSTEPs Data Use Survey
- NBS Continuous Quality Improvement Expert Opinion Survey
- Delphi Process for Identifying Components of Evaluation Tool



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Evaluation Site Visits

Pre-Evaluation Tool

Evaluation Site Visit

Comprehensive report

Recommendations



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SOURCE: APHL



March 07, 2013 15:22 ET

Newborn Screening Program Chooses Web Designer

SILVER SPRING, MD--(Marketwire - Mar 7, 2013) -- The Association of Public Health Laboratories (APHL) is pleased to announce its selection of 5AM Solutions, Inc. to develop and maintain the Newborn Screening Technical assistance and Evaluation Program (NewSTEPS) interactive website and data repository for newborn screening. By virtue of this partnership, States will have access to a robust and dynamic database that will allow them to improve the efficiency and enhance the quality of services they provide to newborns.

NewSTEPS, a program of APHL, is designed to help facilitate newborn screening initiatives and improve programmatic outcomes and outcomes for newborns, thus improving the overall quality of the newborn screening system. APHL is collaborating with the faculty from the Colorado School of Public Health who provide expertise in epidemiology and program evaluation. NewSTEPS is funded through a five-year cooperative agreement by the Genetics Services Branch of the U.S. Health and Human Services Health Resources and Services Administration (HRSA).

"We are looking forward to working collaboratively with 5AM Solutions to build a resource that will give state newborn screening programs, partner organizations and stakeholders access to a



Interactive Website

The screenshot shows the NewSTEPS website homepage. At the top left is the NewSTEPS logo, a program of the Association of Public Health Laboratories. The top navigation bar includes links for HOME, STATE PROFILES, and NEWSTEPS DATA REPOSITORY. Below this is a secondary navigation bar with ABOUT and CONTACT links, a search box, and a dropdown menu currently showing "NBS Laboratory, Follow-Up, and Medical Personnel", "Parents and Caregivers", and "Policy Makers and Administrators". The main content area features a large banner with a purple overlay containing the text "Our Vision" and "Dynamic newborn screening systems have access to and utilize accurate, relevant information to achieve and maintain excellence through continuous quality improvement." Below the banner are four content boxes: "About NewSTEPS" (describing the program), "STATE PROFILES" (with a "Explore profiles" button), "DATA REPOSITORY" (with a "Visit Data Repository" button), and "TECHNICAL ASSISTANCE" (with a "Learn more" button).



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In Collaboration with Colorado School of **Public Health**

Voluntary Data Repository

NewSTEPS Data Repository

The innovative [Data Repository](#)® will serve as a central link for access to newborn screening information, data, and resources across the country.

Purpose: Provide tools to state newborn screening systems to adequately evaluate, analyze, and benchmark the performance of their tests and the quality of their newborn screening programs



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Components of Data Repository

The screenshot shows the NewSTEPS Data Repository website. At the top left is the NewSTEPS logo, a program of the Association of Public Health Laboratories. Navigation links for HOME, STATE PROFILES, and NEWSTEPS DATA REPOSITORY are at the top right, along with a Sign In button. The main content area features the text "Please select a state" above a map of the United States with state abbreviations. To the right of the map is a grid of buttons for states: VT, RI, MD, NH, CT, DC, MA, NJ, and DE. The footer contains copyright information for 2013, the email newsteps@aphl.org, and logos for NewSTEPS, APHL (Association of Public Health Laboratories), and the Colorado School of Public Health.

State Profiles | Baby Level Data | Quality Indicators

Quality Indicators

- QI 1. Percent of invalid dried blood spot specimens due to improper collection and/or transport
- QI 2. Percent of dried blood spot specimens missing essential information
- QI 3. Percent of eligible infants not receiving valid newborn screening test, stratified by dried blood spot or point of care test(s).
- QI 4. Percent of loss to follow-up
- QI 5. Time elapsed from birth to screening, follow-up testing, confirmed diagnosis
- QI 6. Percent of out of range results
- QI 7. Frequency of condition detected by newborn screening for each disorder
- QI 8. Percent of missed cases (false negatives), stratified by disorder



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Disease Specific Outreach

- Critical Congenital Heart Disease (CCHD)
 - Monthly Technical Assistance (TA) calls
 - Working with other groups to develop resources
- Cystic Fibrosis Foundation
 - Discussions about connecting NewSTEPS repository with CFF long term registry

Summary- NewSTEPS

- NewSTEPS is partnering with newborn screening programs to:
 - Provide technical assistance and resources
 - Collate and summarize data in aggregate form
 - Develop opportunities for quality improvement, locally, regionally, and nationally

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