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 Staff

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SOURCE: Association of Public Health Laboratories (APHL)

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.
NewSTEPs Activities

- Continuous Quality Improvement
- Partnerships & Outreach
- Site Visits
- Disease Specific Activities
- Quality Indicators
- Website & Data Repository
- Case Definitions
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
Relationship Building

Regional Collaboratives

National Meetings

Creating a National Presence
Program Evaluation and Community Input

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

Pre-Evaluation Tool

Evaluation Site Visit

Comprehensive report

Recommendations

NewSTEPs
A Program of the Association of Public Health Laboratories™
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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 wealth of information, and data that can support their work to improve newborn screening and health outcomes," said APHL President and CEO Linda F. Pritchard, MD, MPH, FAAPLD.
Our Vision
Dynamic newborn screening systems have access to and utilize accurate, relevant information to achieve and maintain excellence through continuous quality improvement.
Voluntary Data Repository

**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.
Components of Data Repository

State Profiles | Baby Level Data | 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
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
Contact Us

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