

# NewSTEPs: Year 2

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Manager

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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)

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

May 30, 2012



June 25, 2014 14:39 ET

### Newborn Screening Cooperative Agreement Awards \$3.4 Million to APHL

SILVER SPRING, MD--(Marketwire - Jun 25, 2014) - The Association of Public Health Laboratories (APHL) has been awarded a four-year cooperative agreement of up to \$3.4 million by the Genetic Services Branch of the US Health and Human Services Health Resources and Services Administration (HRSA) to maintain and manage the Newborn Screening Technical assistance and Evaluation Program (NewSTEPS). In partnership with the [Colorado School of Public Health \(CSPH\)](#), NewSTEPS provides quality improvement initiatives for newborn screening systems, a data repository and technical and educational resources to state newborn screening programs and stakeholders.

Named one of the [ten greatest public health achievements](#) of the 20<sup>th</sup> century, newborn screening is routinely performed in the US on over four-million newborns annually and saves or improves the lives of more than [12,000 babies](#). For babies who test positive for one of the genetic, metabolic, heart or hearing conditions, newborn screening can prevent serious health problems or even death.

"Our primary goal is to protect the health of babies born in the US," said Jelili Ojodu, director of the [Newborn Screening and Genetics Program](#) at APHL and director of NewSTEPS. "NewSTEPS will allow us to provide states with robust and comprehensive tools that will allow them to improve the efficiency of the services they provide to newborns."

NewSTEPS helps facilitate newborn screening initiatives and improve programmatic outcomes

June 25, 2014



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# Goals

1. Strengthen the newborn screening system through enhancement of the existing **network** of stakeholders by creating a culture of trust, by providing opportunities for timely, **interactive communications**, and by offering a forum for **collaboration** among national, regional, and state NBS programs.
2. Facilitate continuous **quality improvement** and **data-driven** outcome assessments in the NBS system by providing a **standardized repository** and by supporting the integration of **health information technology** frameworks, including HL7 messaging.
3. Create a dynamic national newborn screening **technical assistance resource center** that proactively provides training, addresses challenges, and supports program improvement through partnerships with key stakeholders throughout the NBS community.



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NewSTEPS Steering  
Committee

Health Information  
Technology Work Group

Andrew Richardson (FL)  
Pat Scott (DE)

Critical Congenital Heart  
Disease Work Group

Lisa Hom (Children's National)  
Amy Gaviglio (MN)

Short Term Follow Up  
Work Group

John Thompson (WA)  
Carol Johnson (IA)

Data Repository Work  
Group

Willie Andrews (VA)

Data Request Review  
Subcommittee\*

TBD



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State Representation on NewSTEPS Projects, Work Groups & Activities

State	Steering Committee	Quality Indicators Work Group	Data Repository Work Group	Website Work Group	Evaluation Tool Work Group	CCHD Work Group	Case Definitions Pilot Testing	Workshop Consultants	Repository Data Feedback/Beta Testing	QI/Case Definition Meeting 2012	Registered State Admin	STFU Work Group	QI Feedback	Title V Education Calls	NBS HIT Work Group
Alabama							•			•	•		•		
Alaska											•		•		
Arizona		•								•	•				
Arkansas											•		•		
California	•									•	•				•
Colorado	•			•			•			•	•	•			
Connecticut											•				
Delaware							•		•	•	•	•			•
District of Columbia										•	•				
Florida	•	•								•	•		•		•
Georgia						•				•	•		•		•
Hawaii				•			•			•	•		•		
Idaho											•		•		
Illinois											•		•		
Indiana										•	•				•
Iowa	•	•	•				•		•	•	•	•	•		•
Kansas		•				•	•		•	•	•		•	•	
Kentucky				•							•		•		•
Louisiana							•			•	•				
Maine											•				
Maryland	•					•	•			•	•		•		
Massachusetts	•	•					•			•	•				•
Michigan					•	•					•				
Minnesota						•		•		•	•	•	•		•
Mississippi										•	•		•		
Missouri					•		•		•	•	•	•	•		



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Listserv

Regional  
Collaboratives

Outreach

Website

National  
Webinars



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# Technical Assistance Webinars

Short Term Follow Up	
Number of Webinars	6
Inaugural Webinar	November 2013
Topics	Genetic Counseling and NBS
	NBS Education
	False Negatives and Missed Cases
	When is Enough Enough?
Health Information Technology	
Number of Webinars	3
Inaugural Webinar	April 2014
Topics	Data Messaging Standards
	HIT Program Experiences



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# Critical Congenital Heart Disease

Webinars	
Number of Webinars	19
Topics	Needs of CCHD Community
	Out of Hospital Births
	Challenges of CCHD at Altitude
	Pulse Oximetry Equipment
	Legislative Changes
	Data Collection
	In-Person Meeting
Date	February 2014
Participants	>80 participants; All 50 states invited



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# Quality Practice Resources

Case Definitions Quality Indicators **Disorder Specific Activities** Model Practices Short Term Follow Up

## Disorder Specific Activities

- **Critical Congenital Heart Disease (CCHD)**
- **Severe Combined Immunodeficiency (SCID)**
- **Pompe Disease**

### Educational Resources

#### PUBLICATIONS

Indicators of newborn screening for congenital hypothyroidism in Sri Lanka: program challenges and way forward

This article analyzed the newborn screening system in Sri Lanka in the areas of sample...

#### PUBLICATIONS

Newborn screening for Pompe



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# SCID

*Now accepting applications for  
funding to support programs  
working towards full  
implementation of SCID  
Newborn Screening*

*IMPLEMENTATION OF  
SEVERE COMBINED  
IMMUNODEFICIENCY  
(SCID)*

*FUNDING OPPORTUNITY*

## **APPLICATION DETAILS**

Application due date: November 24, 2014

For more information and application instructions please  
visit: <https://www.newsteps.org>



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*The development of this request for proposals application was supported by Cooperative Agreement Number UG5MC27837. NewSTEPS is funded under Cooperative Agreement #U22MC24078 from HRSA. NewSTEPS is a collaboration between the Association of Public Health Laboratories and the Colorado School of Public Health*

# Training

- **Who:** 8 participants
- **What:** Tandem Mass Spec. Follow Workshop
- **Where:** Raleigh, NC (Duke University)
- **When:** March 2015 | Annually
- **Why:** To complement existing training opportunities offered by APHL; Professional development with a focus on follow-up.



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# Evaluation Site Visits



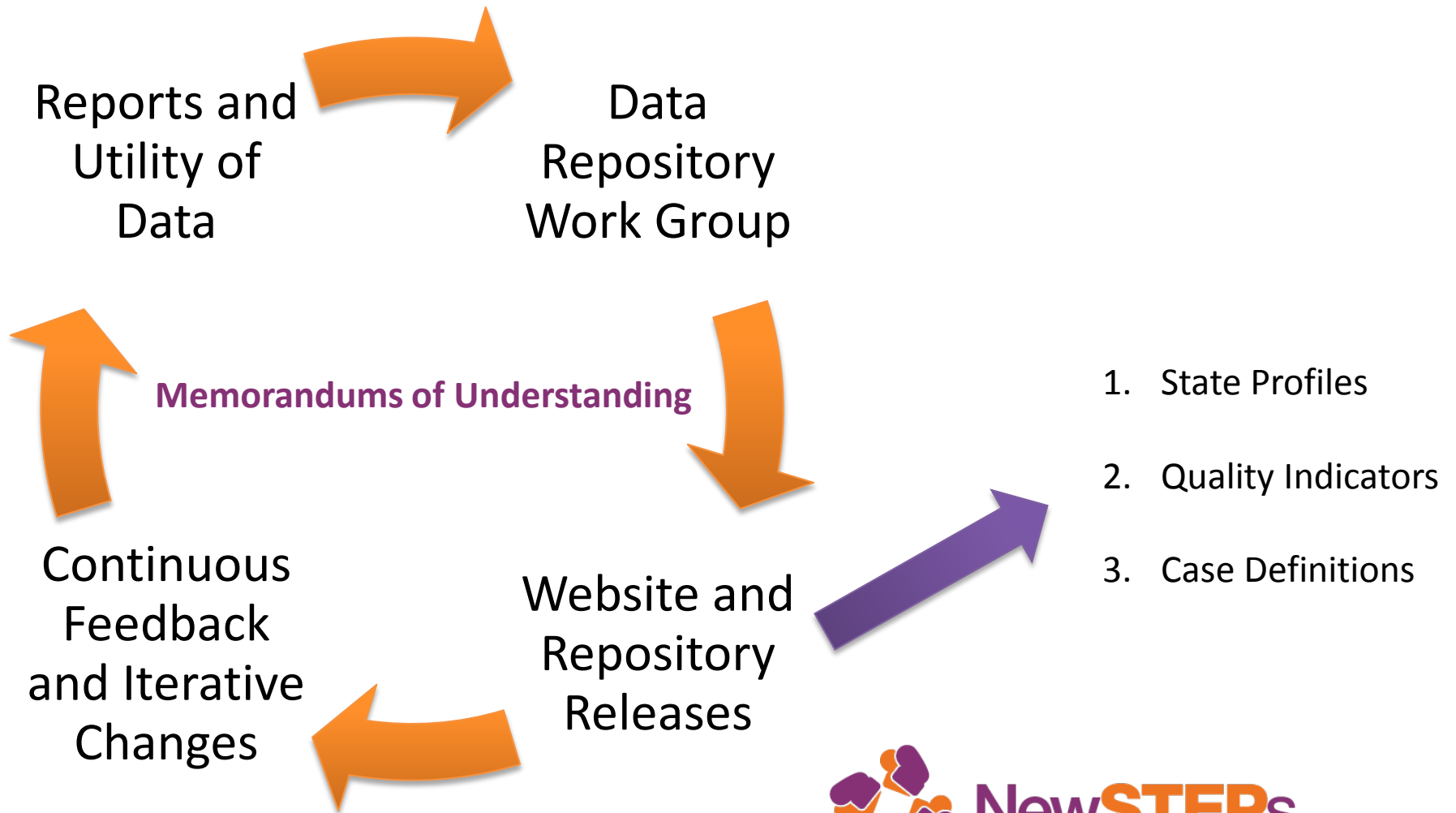
- **Iterative Process**
- **Pre-Evaluation Forms**
- **Customized Evaluation Team**
- **Comprehensive Report**
- **Recommendations**



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# Re-Assessing Business as Usual



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# COIIN

*NewSTEPS is accepting applications for teams interested in improving the timeliness of NBS sample collection, transport and delivery*

*Collaborative Improvement and Innovation Network (CoIIN) for Timeliness in Newborn Screening*

*A Quality Improvement Opportunity for State Newborn Screening Programs*

*Teams will build on current activities to develop and implement quality improvement activities to address timeliness in pre-analytic phases of NBS*

## APPLICATION DETAILS

Application due date: November 10, 2017

For more information and application instructions please visit: <https://www.newsteps.org>

**NOVEMBER 10**



# 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

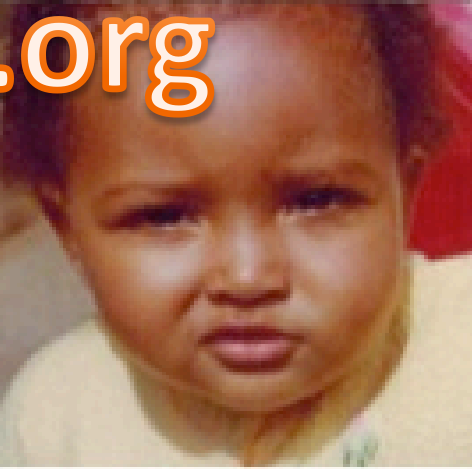
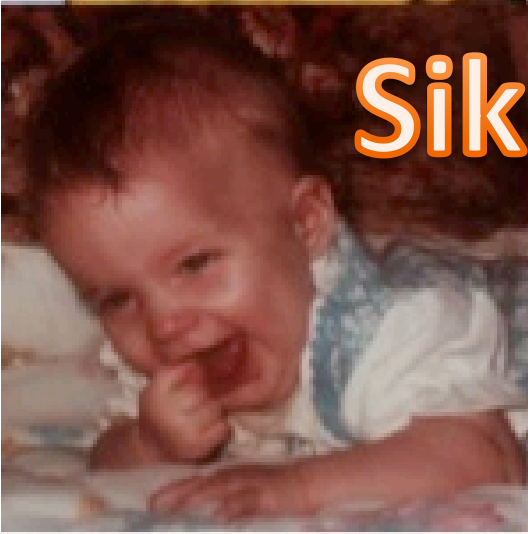




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