

NewSTEPs

**Newborn Screening Technical assistance
and Evaluation Program**

Marci Sontag, PhD
Director of Epidemiology, NewSTEPs
Colorado School of Public Health

Overview

NewSTEPs

will provide quality improvement initiatives,
a new innovative data repository,
and technical and educational resources
*to state newborn screening programs
and stakeholders.*

Structure

- NewSTEPs is funded through a five-year cooperative agreement to APHL by the Genetic Services Branch of the Health Resources and Services Administration (HRSA)
 - APHL
 - Director of NewSTEPs: Jelili Ojodu, MPH
 - Senior Advisor: Jane Getchell, DrPH
 - Project manager Sikha Singh, MHS
 - Senior Specialist (TBD)
 - CDC Liaison: Elizabeth Jones, MPH
 - APHL staff is collaborating with Colorado School of Public Health
 - Marci Sontag, PhD (Director of Epidemiology)
 - Yvonne Kellar-Guenther, PhD (Program Evaluator)
 - NewSTEPs Steering Committee

Established Collaborations

- State Newborn Screening Programs
- Regional Collaboratives and the National Coordinating Center
- Newborn Screening Clearinghouse (Baby's First Test)
- Newborn Screening Translational Research Network (NBSTRN)
- Center for Disease Control and Prevention (CDC)

Goal 1 – Information gathering, building relationships

- Identify gaps and barriers:
 - NBS education
 - PH decision makers
 - NBS program personnel (new disorders, new assays, follow-up strategies.)
 - Communication
 - Data collection and reporting
- Build and strengthen relationships among local, state, regional, and national NBS stakeholders, private partners, and NewSTEPS.
- IMPACT: Use information from the NBS community to strengthen NewSTEPS going forward. Develop a program that will support states and NBS stakeholders

Goal 2 – Education, Networking

- Create and support a NBS network for education and communication
 - Local
 - State
 - National
- IMPACT: Networks of individuals can be utilized to improve newborn screening outcomes
 - In Person and Virtual Networking
 - Sharing Successes/Challenges

Goal 3 – Data repository

- Design, build, and validate a data repository system
 - Evaluation of newborn screening systems
 - Quality improvement and monitoring of changes in systems
 - Disorder occurrence, practices, etc.
- Impact:
 - Use quality indicators to improve newborn screening programs at state, regional, and national level
 - Identify trends at state, regional, national levels
 - Long term: Benchmarking, networking between states

Goal 4 – Technical Assistance

- Build on existing technical assistance and training opportunities for both individuals and programs providing NBS services.
 - Pre-analytic
 - Analytic
 - Post-analytic
 - Short term follow-up
 - Point of Care
- Voluntary Newborn Screen Quality Certificate Program

Impact:

Site visits will be provided under HRSA funding

Improved Educational Resources

Quality Certification Program could be used as point of pride in NBS programs or identify need for more resources

Highlights of the First Year

- July 2012 – October 2012
 - Quality Indicators – Modify and finalize
 - Case Definitions – Finalize case definitions
 - Engage NBS community and get input
- August - October 2012
 - Define the structure and component of Data Repository, advertise RFI, and begin development
 - Hire NewSTEPS Staff
- January – May 2013
 - Work with NBS laboratory system vendors to identify possibilities for data transfers
 - Host Webinars to demonstrate repository
- May 2013
 - Debut repository at NBSGT and ISNS Symposium (Atlanta)

We want to hear from you

- Let us know what you would like to see in:
 - Technical Assistance
 - Data Repository
 - Education
 - Quality Improvement
 - Networking
- At this meeting:
 - NewSTEPS Table
 - Lunch
 - NBS Workgroup
 - Survey
- This fall
 - Surveys
 - Interviews
 - Contact us

Complete our SURVEY:

<http://www.surveymonkey.com/s/NewSTEPS>

Contact Us

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