Session 6 – Teach and Preach: Education Initiatives

Wednesday, Oct. 29 – 8:30am-10:00am

Moderators – Natasha Bonhomme, Genetic Alliance and Amy Gaviglio, MS, CGC, Minnesota Public Health Laboratory Division

The State of Newborn Screening Systems in the US
M. Sontag1,2, Y. Kellar-Guenther1,2, S. Singh2; 1Colorado School of Public Health, Aurora, CO, 2NewSTEPs, Association of Public Health Laboratories, Silver Spring, MD

Abstract

Background: The NewSTEPs data repository serves as the central location for access to newborn screening (NBS) data, information and resources. The repository is accessible to authorized users and allows NBS programs to explore data to help meet program needs. NBS programs that enter data into the repository have access to their own data as well as to aggregate data from other participating NBS programs.

Objective: NewSTEPs aims to provide relevant, up-to-date data on NBS programs in the U.S.

Methods: State profiles contain high level demographic, policy, program, and screening information that can be viewed by the public. State NBS programs can edit NBS data with updates reflected on the website in real time. State and aggregate level data are made available to stakeholders utilizing reporting mechanisms with various levels of access. Aggregated data from the NewSTEPs repository state profiles are presented, representing the 50 states and the District of Columbia.

Results: State screening programs serve newborn populations ranging in size from 6,100 births per year to over 500,000 (median 52,200). Regional laboratories serve 13 states, while all states have their own short term follow-up programs. Funding of NBS activities is secured from different sources, however most programs (n=47/51) have an NBS fee (median $71, range $15 – 157). Length of time to store residual dried blood spots ranges from 1 month to more than 27 years, with a median of 1 year. New disorders are added to state NBS panels via a variety of mechanisms (legislation n=22, commissioner/board of health n=18, other n=2, unknown n=9). As of June 1, 2014, 17 states have implemented state-wide screening for severe combined immunodeficiency (SCID), while 18 have state-wide screening for critical congenital heart disease (CCHD).

Conclusion: NewSTEPs is the central source for information on NBS program data. Quality indicator and disorder frequency data will be available later in 2014. Reports are available on the NewSTEPs website, with maps and interactive info graphics depicting a wide variety of information, and provided in a manner that showcases a national snapshot of NBS programs.

Presenter: Marci Sontag, PhD, Colorado School of Public Health, Aurora, CO & NewSTEPs, APHL, Silver Spring, MD, Phone: 303.724.4430, Email: marci.sontag@ucdenver.edu
What Parents Want to Know about the Storage and Use of Residual Newborn Bloodspots
J. Botkin, E. Rothwell, R. Anderson and N. Rose, University of Utah, Salt Lake City, UT

Abstract

Objectives: Many state newborn screening programs retain residual newborn screening bloodspots for a variety of purposes including quality assurance, biomedical research, and forensic applications. This project was designed to determine the information that prospective parents want to know about this practice.

Methods: Eleven focus groups were conducted in four states. Pregnant women and their partners and parents of young children (N=128) were recruited from the general public. Focus group participants viewed two educational movies on newborn screening and DBS retention and use. Transcripts were analyzed with qualitative methods and the results were synthesized to identify key information items.

Results: We identified 14 categories of information from the focus groups that were synthesized into seven items prospective parents want to know about residual DBS. The items included details about storage, potential uses, risks and burdens, safeguards, anonymity, return of results, and parental choice.

Conclusions: For those state programs that retain residual dried bloodspots, inclusion of the seven things parents want to know about residual dried bloodspots in educational materials may improve parental understanding, trust, and acceptance of the retention and use of stored bloodspots.

Presenter: Erin Rothwell, PhD, CTRS, University of Utah, Salt Lake City, UT, Phone: 801.230.8456, Email: erin.rothwell@nurs.utah.edu

Summary

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Conclusions: For those state programs that retain residual dried bloodspots, inclusion of the seven things parents want to know about residual dried bloodspots in educational materials may improve parental understanding, trust, and acceptance of the retention and use of stored bloodspots. We found that parents are open to the retention and use of DBS but expect to be told about storage of DBS and to have a choice regarding whether or not their infant’s DBS will be retained for future research. The key informational requirements identified by the participants are relatively simple and could be conveyed through a brochure or audiovisual presentation.

The Seven Things Parents Should Know about Residual Dried Bloodspots

1. Some states save leftover bloodspots after newborn screening is complete.
2. Leftover bloodspots can be used to improve the public’s health in many ways.
3. No extra heel pricks are done to collect blood for other potential uses of the spots.
4. Safeguards are in place to protect the privacy of babies and families and to ensure the ethical conduct of research.
5. The baby’s name or other identifiable information is not attached to the leftover bloodspots used in most research.
6. Because most research with leftover bloodspots is done anonymously, parents will usually not get results back from the research.
7. A parent may request that their baby’s bloodspot not be used in research after newborn screening.

Developing and Maintaining Parent Fact Sheets for Newborn Screening: A Decade of Multi-State Collaboration
S. Mann and L. Hasegawa, Hawaii Department of Health, Honolulu, HI

Abstract

Fact sheets for parents on disorders on the newborn screening (NBS) panel were initially developed in 2004 as part of a Health Resources and Services Administration funded project to provide resources to help parents and providers as NBS panels expanded with the introduction of tandem mass spectrometry. The fact sheets were developed as a multi-state (Alaska, California, Hawaii, Idaho, Oregon and Washington) effort with input and review by NBS program staff, genetics and other specialists, parents, and primary care providers.

The fact sheets were developed to help parents in the period between receiving the initial contact that their baby has a positive NBS result and their visit with the clinical specialist. We recognized that this is a particularly anxious time of information seeking for parents and wanted to give them a trusted information source.

The fact sheets are written at the 7-8th grade reading level according to the Flesch-Kincaid scale. Difficult or technical terms are hyperlinked to a pop-up glossary. The information is organized based on feedback from surveys and focus groups of parents. There is information about what causes the disorder, symptoms, treatments, genetics, testing, and links to support groups and more information. The fact sheets are available on the website (www.newbornscreening.info) and downloadable in PDF. The fact sheets are copyright free so that any NBS program can use them with their own branding. Our only requirement is that the website URL is part of their information so that parents can find the original source in case the information has been updated. Fact sheets are reviewed and revised about every two years. Fact sheets for new disorders are developed, reviewed and posted as the participating states add disorders from the Recommended Uniform Screening Panel.
The parent fact sheets have been maintained for a decade now. The feedback is that many parents, primary care providers and specialists use the fact sheets. Current statistics show that about 20,000 unique visitors go the website each month. In 2013, there were 286,000 unique visits.

Information will be presented on the ten year experience with the use of the parent fact sheets, challenges to maintaining current and developing new fact sheets, and future plans to enhance the information available.

**Presenter:** Sylvia Mann, MS, Hawaii Department of Health Genomics Section, Honolulu, HI, Phone: 808.733.9063, Email: sylvia@hawaiigenetics.org

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**A Comprehensive Resource for US Newborn Screening Programs: NewSTEPs Year Two**

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**Abstract**

**Background:** In June 2013, NewSTEPs (the Newborn Screening Technical assistance Evaluation Program) embarked on its second year of activities and has been a critical component in ensuring that states can adequately evaluate, analyze, and benchmark the performance of their tests and the quality of their Newborn Screening (NBS) programs. NewSTEPs has worked over the past year to facilitate newborn screening initiatives and improve programmatic outcomes by offering a comprehensive data repository, educational resources, and technical assistance to newborn screening programs. NewSTEPs activities are guided by a Steering committee of newborn screening stakeholders and liaisons who met on a monthly basis.

**NewSTEPs Activities in Year 2:**

- Participated in Annual Meetings of the Regional Collaboratives to present the goals and objectives of the program.
- Interviewed key stakeholders, including Title V directors, to ensure inclusive and wide-spread engagement of participants in newborn screening systems;
- Debuted the NewSTEPs Data Repository, providing public state profiles, case definitions for NBS disorders and quality indicators developed by the NBS community;
- Conducted two Site Evaluation Visits using a new, peer-developed Site Visit Evaluation tool;
- Developed Technical Assistance activities for Critical Congenital Heart Disease (CCHD) screening implementation, Short Term Follow Up, and Health Information Technology (HIT) activities.
- Developed a dynamic and comprehensive website: [https://newsteps.org](https://newsteps.org) that provides resources to support NBS activities.

**Conclusion:** NewSTEPs supports NBS programs by providing data, technical and educational resources to various NBS stakeholders. The program facilitates harmonization of NBS activities through innovation and technology with the goal of continuous quality improvement. The foundation for all NewSTEPs activities is built upon ongoing community engagement, trust building and transparency.

Presenter: Sikha Singh, MHS, PMP, NewSTEPs, Association of Public Health Laboratories, Silver Spring, MD, Phone: 240.485.2726, Email: sikha.singh@aphl.org

Summary

The Newborn Screening Technical assistance and Evaluation Program (NewSTEPs) is a national newborn screening program designed to provide data, technical assistance, and training to newborn screening programs across the country and to assist states with quality improvement initiatives. NewSTEPs is a comprehensive resource center for state newborn screening programs and stakeholders.

NewSTEPs is funded through a cooperative agreement to the Association of Public Health Laboratories (APHL) by the Genetic Services Branch of the Health Resources and Services Administration (HRSA). NewSTEPs functions with the goal of improving outcomes for newborns by facilitating of the newborn screening system. State programs benefit from the shared resources that NewSTEPs offers, including a data repository, interactive website, technical assistance, education and training, policy guidance and program evaluation.

NewSTEPs staff collaborate with partners in state newborn screening programs and newborn screening stakeholders across the country. These collaborations are realized through the NewSTEPs Steering Committee, workgroups to guide daily activities, and partnerships with other NBS organizations at the regional and national levels.

Newborn screening (NBS) is a public health program that entails many components including testing, diagnosis, follow-up, treatment, education and evaluation. In the United States, four and a half million newborns receive newborn screening annually. The Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) evaluates and recommends disorders to be included on the Recommended Uniform Screening Panel (RUSP). Each state, however, mandates the specific disorders to be tested, implements a screening process including follow-up of out-of-range results, and is responsible for quality improvement of the entire newborn screening system.

The formation of a Newborn Screening Technical assistance Evaluation Program (NewSTEPs) has been a critical step in ensuring that states can adequately evaluate, analyze, and benchmark the performance of their tests and the quality of their NBS programs. To be effective and successful, NBS systems require partnerships that include families, health care providers, and local, regional, state, national and private organizations. The activities of NewSTEPs are designed to build partnerships with the ultimate goal of improving quality in the NBS system.

The purpose of NewSTEPs is to expand upon previous quality improvement efforts and strengthen existing newborn and genetics screening programs by providing data, technical and educational resources to various NBS stakeholders. The project entails facilitating the harmonization of newborn screening activities through innovation and technology with the goal of being able to analyze, compare and continuously improve NBS systems.