NewSTEPs Data Repository: A Resource for the Newborn Screening Community

www.newsteps.org

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The development of this presentation was supported by Cooperative Agreement #U22MC24078 from the Health Resources and Services Administration (HRSA). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of HRSA.

APHL is collaborating with the Colorado School of Public Health to implement NewSTEPs.
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.
How Can I Access It?

NewSTEPs Data Repository

The innovative Data Repository serves as a central link for access to newborn screening information, data, and resources across the country.

About NewSTEPs

The Newborn Screening Technical assistance and Evaluation Program (NewSTEPs), 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), provides quality improvement initiatives, an innovative data repository and technical resources for newborn screening programs.
Components of Data Repository

- Cases
- State Profiles
- Quality Indicators

Data Repository
Select a state or click here to view aggregate reports.
California State Profile

Year: 2012

Name of State NBS Program:
California Newborn Screening Program/Genetic Disease Screening Program

Region:
Western States Genetic Services Collaborative (WSGSC)

Website:
http://www.cdph.ca.gov/programs/NBS/Pages/default.aspx

Annual Births:
510,000
Reports

Select a state or click here to view aggregate reports.
Range of Initial Newborn Screening Fees in the United States

- No Fee: 4
- Upto $50: 9
- $51-$100: 28
- Greater than $100: 10
Interactive Reports and Queries

Select a state or click here to view aggregate reports.
## Screened Conditions Report

### Other Disorders

<table>
<thead>
<tr>
<th>Condition</th>
<th>Universally Required</th>
<th>Universally Offered</th>
<th>Offered Select</th>
<th>Considered</th>
<th>Req Not Implemented</th>
<th>Likely Detected</th>
<th>Pilot Tested</th>
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<tbody>
<tr>
<td>Biotinidase deficiency - BIOT</td>
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<td></td>
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<tr>
<td>Critical congenital heart disease - CCHD</td>
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<td>Cystic fibrosis - CF</td>
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<td>Classic galactosemia - GALT</td>
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<td>Hearing loss - HEAR</td>
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<tr>
<td>Severe Combined Immunodeficiencies - SCID</td>
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</table>
Sample Report Graphic: Quality Indicators

Percent of infants receiving screening in specified time intervals

All data portrayed in this sample report are fictitious. Data do not represent actual outcomes from any newborn screening program. Any resemblance to real data from a real newborn screening program is completely coincidental.
Making Data Entry Easier

Current
- Manual Data Entry

IN PROGRESS
- Pilot with NBS Programs
- Working with LIMS vendors*

Future
- Electronic Data Transfer
- Reports from state LIMS

*PerkinElmer, Natus/Neometrics, StarLIMS, OZ Systems
You Have Control!
Technical Assistance: HIT

Webinars | Work Group | Implementing Data Standards

- Workgroup goals:
  - Serve as a resource for NBS programs as they navigate through HIT
- Webinars ongoing every other month
- Support the integration of health information technology frameworks, including HL7 messaging
- Support technical assistance for NBS program in development of data standards
Conclusion

• Reports, access to aggregate and individual information
• Inform quality improvement activities
• Continuous quality improvement