2019 APHL Newborn Screening and Genetic Testing Symposium

Strong Foundations Lead to New Heights
The State of Newborn Screening in the United States

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April 7, 2019

This work was supported under Cooperative Agreement #U22MC24078 between the Association of Public Health Laboratories and HRSA. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of HRSA.
Thank You!

Ona Adair  
Aderonke Adewuyi  
Nancy Althouse-Hill  
Sabra Anckner  
Wanda "Willie" Andrews  
Karen Andruszewski  
Laura Ashbaugh  
Wanda Atha  
Kathryn Aveni  
Mei Baker  
Rebecca Barnett  
Kristin Barnette  
Krystal Baumert  
Rebecca Bausinger  
Amanda Bawcom  
Jennifer Baysinger  
Linda Beischel  
Stanton Berberich  
Sonal Bhakta  
Christianne Biggs  
Michelle Black  
Keith Bock  
Gregory Bonn  
Frances Bonnin-Sorrelles  
Amy Gaviglio  
Ofelia Gentscheff  
Annelise Gile  
Nancy Giurato  
Teresa Goad  
Fizza Gulamali-Majid  
Stacey Gustin  
Soheila "Sue” Haddad  
Arthur Hagar  
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Catherine Harbison  
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Karen Hess  
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Leslie Himstedt  
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Lauren Noll  
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Ashley Porter  
Pat Purifoy  
Ashleigh Ragsdale  
Emily Reeves  
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Rachael Montgomery  
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Hanna Pitts  
Ashley Porter  
Pat Purifoy  
Ashleigh Ragsdale  
Emily Reeves  
Brendan Reeves
Outline

• Who are we?
• How are we doing?
• What’s on the horizon?
• Success Story
What Components Make Up a Newborn Screening System?

• Parents/Families
• Birthing facilities
• Courier/shipping companies
• NBS Program
  – laboratory
  – Short-term Follow-up
• Medical providers (Nurses, PCPs, specialists, etc.)
• Policy makers
• Insurance companies
• Private laboratories
U.S. Newborn Screening Programs

2017 Annual Births
Minimum = 3,297
Maximum = 471,658
Median = 50,214

U.S. Newborn Screening Programs

- 36 state NBS laboratories
- 5 regional NBS laboratories

Regional Laboratory

State Served by Regional Lab
Sample Dried Blood Spot Cards

| Last Name | First Name | Gender | Birth Date | Birth Time (Military) | Birth Wt. (grams) | Who Gave Birth | Gave Birth A | Gave Birth B | Gave Birth C | Single Birth | Multiple Birth | Antibiotics |
|-----------|------------|--------|------------|-----------------------|-------------------|---------------|---------------|-------------|-------------|-------------|--------------|--------------|-------------|
|           |            |        |            | MM/DD/YY HH:MM        |                  |               |               |             |             |             |              |              |             |

**MEDICAL RECORD #**

- NICU: NICU or Special Care
- NIV: Non-Invasive Ventilation
- TPN: Total Parenteral Nutrition
- Amino Acids
- HEC: Hepatitis C
- NICU: NICU or Special Care
- Yes
- No

**Type of Collection**

- heel stick
- capillary draw
- line draw (central, other)

**Type of Flush**

- Hepatitis A/BC
- HIV
- HBV

**Mother**

- Last Name
- First Name
- Address
- City
- State
- ZIP

**Submitter**

- Last Name
- First Name
- Address
- City
- State
- ZIP

**SAME SAMPLE**

- Hospital Code (if applicable)

**DO NOT REMOVE OVERLAY**

See attached instructions for specimen collection and sending.

Allow blood to dry for a minimum of 3 hours using the overlay for support. Close the overlay when dry. Send within 24 hours of collection.

Do not send specimens in plastic bags.

[Biohazard Symbol]

[QR Code]

[Expiry Date: 2020-11-30]
Sample Dried Blood Spot Cards
How many days per week is each newborn screening follow-up program open?
## Information Management of NBS Data

<table>
<thead>
<tr>
<th>Laboratory Information Management System</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internally Developed</td>
<td>8</td>
</tr>
<tr>
<td>Neometrics/ Natus</td>
<td>14</td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
</tr>
<tr>
<td>PerkinElmer</td>
<td>20</td>
</tr>
<tr>
<td>StarLims</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Follow-up Information Management System</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>Internally Developed</td>
<td>17</td>
</tr>
<tr>
<td>Neometrics/ Natus</td>
<td>11</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
</tr>
<tr>
<td>Oz Systems</td>
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</tr>
<tr>
<td>PerkinElmer</td>
<td>10</td>
</tr>
<tr>
<td>StarLims</td>
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<tr>
<td>Unanswered</td>
<td>1</td>
</tr>
</tbody>
</table>
Confirmed Cases Identified Through Newborn Screening

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Cases</th>
<th>Condition with Highest Number of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>6346</td>
<td>CH - 2312</td>
</tr>
<tr>
<td>2016</td>
<td>6202</td>
<td>CH - 2360</td>
</tr>
<tr>
<td>2017</td>
<td>6228</td>
<td>CH - 2284</td>
</tr>
</tbody>
</table>

51 NBS programs reporting on 33 CORE RUSP conditions
Does not include point of care (CCHD and Hearing Loss)
# Time Critical Specimens and Results - 2017

<table>
<thead>
<tr>
<th>Year</th>
<th>Birth to Initial Collection (Median in Hours)</th>
<th>Birth to Initial Receipt (Median in Days)</th>
<th>Birth to Initial Results (Median in Days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>29</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>2016</td>
<td>30</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>2017</td>
<td>31</td>
<td>3</td>
<td>4.5</td>
</tr>
<tr>
<td>Year</td>
<td>Birth to Medical Intervention (Median in Days)</td>
<td>Birth to Diagnosis (Median in Days)</td>
<td></td>
</tr>
<tr>
<td>------</td>
<td>-----------------------------------------------</td>
<td>-------------------------------------</td>
<td></td>
</tr>
<tr>
<td>2015</td>
<td>6</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2016</td>
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<td>12</td>
<td></td>
</tr>
<tr>
<td>2017</td>
<td>5</td>
<td>11</td>
<td></td>
</tr>
</tbody>
</table>
Timeliness

- Birth: 93.99%
- Specimen Collection: 78.47%
- Receipt at Laboratory: 91.00% [all results]
- Results Reporting: 63.78% [time critical results]

- Specimen Collection: 87.25% [non-time critical results]
- Results Reporting: 85.85% [all results]
- Results Reporting: 74.82% [non-time critical results]
- Results Reporting: 40.39% [time critical results]
What is on the horizon?

- Implementation of new disorders
- Advancements in health information technology
- Innovation in communication
- Quality improvement
- Laboratory techniques
Minnesota GovIT Award for Collaboration

From left to right:
• Joanne Bartkus, MDH PHL Lab Director
• Walter Reichert, Natus
• Amy Gaviglio, NBS STFU Supervisor
• Heather Brand, NBS Ops and PM for this project
• Jill Simonetti, NBS Ops Supervisor and business lead for project
• Mark McCann, MDH NBS Manager
• Myra Kunas, MDH PHL Assistant Division Director

Not pictured:
Terese Finitzo, OZ Systems
Visit www.newsteps.org
Email newsteps@aphl.org
NewSTEPs Data Entry Timeline

Case data: Time critical cases due for current year-2
3/15

Quality indicator data due for current year-1
4/15

Case data: Non critical cases due for current year-2
6/15

State profile data: Current year data pulled for annual report generation
8/1

Always
Recommend state profile updates