HRSA PRIORITY 1: TREAT IN THE CONTEXT OF A MEDICAL HOME THAT PROVIDES ACCESSIBLE, FAMILY-CENTERED CONTINUOUS, COMPREHENSIVE, COORDINATED, COMPASSIONATE, AND CULTURALLY EFFECTIVE CARE.
Heartland Collaborative demonstrated a **20%** increase in Medical Home activities in Year 2.

Heartland has implemented less activity than the national average.

Includes: Medical Home IHP, Transition, and Hispanic Access
BUILDING ADVOCACY CAPACITY: STUDENT LEADERSHIP MENTORING

- Participated in Conference with follow-up support

- What Worked?
  - Topics were very informative, e.g. strategies for transition
  - Learned to effectively tell your story
  - Incredible connections with staff, presenters and other students

- How she is going to use?
  - Share information with other families and young adults
  - Use the stress release activities
  - Use skills to become a better advocate
HRSA PRIORITY 3: EXPAND THE POOL OF THE GENETICS SERVICE WORKFORCE BY DETERMINING NEEDS AND GAPS ACROSS SECTORS TO PROVIDE EDUCATION AND TRAINING, WITH EMPHASIS ON ALLIED HEALTH PROVIDERS, OTHER SUBSPECIALTIES AND EDUCATORS.
PARTNERS PROJECT

Participants demonstrated a good understanding of NBS after participation at APHL.

Participants viewed themselves as change agents who could make a difference.

Understand NBS
Are a Change Agent
Can Further State Efforts
Understand Genetics

<table>
<thead>
<tr>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Participants viewed attendance at APHL Conference as an opportunity to expand their knowledge of clinical genetics and NBS.

Information on NBS and Systems Approaches to Follow-Up

Awareness of # and Diversity of Individuals to Implement Screening

Breadth of Services Available and Unique Approaches across States
The majority of the state partners targeted dissemination of information through articles and education activities and their strategy for change.

<table>
<thead>
<tr>
<th>Partners’ Next Step to Action</th>
<th>States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dissemination of NBS information through education opportunities and articles.</td>
<td>AK</td>
</tr>
<tr>
<td>Development of Condition-Related Action Plans</td>
<td>IO</td>
</tr>
<tr>
<td>Policy Position Paper to Increase Infrastructure Supports and Services</td>
<td>MO</td>
</tr>
<tr>
<td>Linkages between state NBS program and Midwives Association</td>
<td>NE</td>
</tr>
<tr>
<td>Establishment of quality improvement process to improve NBS process</td>
<td>OK</td>
</tr>
</tbody>
</table>
EHDI EXCHANGE

- Summarize areas targeted for discussion and change
The ACA Forum resulted in action as state level planning was initiated.

- Using information to inform current policies: 75%
- Posted materials on Web: 57%
- Disseminated materials: 43%
- Support Advocacy work: 43%

Over 75% of the participants strongly agreed that the ACA Forum resulted in increased knowledge about ACA and its related policies.
HRSA PRIORITY 4: BUILD CAPACITY IN STATE PUBLIC HEALTH DEPARTMENTS TO ENHANCE AND SUSTAIN THE DELIVERY OF NEWBORN AND CHILD SCREENING AND GENETIC FOLLOW-UP AND TREATMENT SERVICES.
MAJORITY OF STATES HAVE ADOPTED UNIVERSAL CCHD SCREENING.

STATES HAVE MADE PROGRESS IN ADOPTING CCHD AND SCID SCREENING OVER THE PAST TWO YEARS.

<table>
<thead>
<tr>
<th>Year</th>
<th>States Adopting Universal CCHD Screening</th>
<th>States Implementing Partial or Universal SCID</th>
</tr>
</thead>
<tbody>
<tr>
<td>2013</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>2014</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>2015</td>
<td>7</td>
<td>4</td>
</tr>
</tbody>
</table>
HRSA PRIORITY 8: EXPAND STATE AND REGIONAL COLLABORATIVE SYSTEMS OF COHORTS OF PATIENTS FOR LONG-TERM MONITORING AND ANALYSIS OF FOLLOW-UP AND TREATMENT FOR PROVIDER AND/OR PATIENT ACCESS.
4 STATES PARTICIPATE IN LONG TERM FOLLOW-UP PILOTS IN 2013-2014

- Oklahoma
- South Dakota
- Nebraska
- Missouri
HRSA PRIORITY 10: BUILD CAPACITY IN STATE PUBLIC HEALTH DEPARTMENTS TO ENHANCE AND SUSTAIN THE DELIVERY OF NEWBORN AND CHILD SCREENING AND GENETIC FOLLOW-UP AND TREATMENT SERVICES.
Lest We Forget, The Heartland is Hazardous!

Missouri Flooding
July 30th, 1993

Ankeny, Iowa
June 18th, 1974 @ 10:30 PM
Category 4 Tornado, 2 Miles Wide
AR/ MO NBS LABORATORY DRILL, 2014

▪ First planning conference call in April, 2014
▪ Face to face planning meeting in Little Rock on May 13th
▪ Reserved August 12th for drill date with backup date of August 20th (August 20th was used)
▪ AR was disaster state with MO as assisting state
▪ 200 NBS samples utilized
▪ EMAC’s Mission Ready Package (MRP) process was utilized for the first time for NBS
▪ The AR Civil Air Patrol was utilized to fly the samples to MO
HIGHLIGHTS FROM THE AR/MO DRILL

▪ First NBS drill to use EMAC’s MRP process
▪ Drill began at 8:00 am and all EMAC approvals were attained by 11:15 am
▪ The AR Civil Air Patrol volunteered to transport the NBS samples by plane straight over the Ozarks mountains from Little Rock to Jefferson City (this served as a drill for them too)
▪ MO State Lab received AR’s samples at 12:30 pm that same day
▪ Sample processing in MO began at 1:00 pm
▪ The 200 NBS samples’ parallel testing showed the same 3 presumptive positive (referred) screens for both states
▪ This was the best, fastest and smoothest drill we have ever conducted in the Heartland (This was Drill #16)
NATIONAL DATA

Heartland Regional Data
THE MAJORITY OF HEARTLAND’S TRAINING TARGETED MEDICAL HOME.
Heartland Collaborative mirrored the national percentages in types of individuals participating in Collaborative activities.

- **Advocacy Organizations**: Heartland Avg 13, National Avg 11
- **Family Organizations**: Heartland Avg 11, National Avg 13
- **Consumers**: Heartland Avg 87, National Avg 88
- **Providers**: Heartland Avg 88, National Avg 87
INDIVIDUALS ACCESS THE HEARTLAND COLLABORATIVE WEBSITE PRIMARILY FOR INFORMATION ON MEDICAL HOME AND COLLABORATION.
Email distribution on May 4th
If you were not present during this presentation, please use this link https://www.surveymonkey.com/r/5TTC892 to access the evaluation form. We value your opinion and your suggestions will help us improve future Heartland events. Please respond by Monday, May 18 by COB.
THANKS!!