Heartland Regional Genetics Network (HRGN) Preliminary Annual Data 2022-2023
What were our Strategies and Results?
Family Consultants and Health Care Providers Support Access to Genetics through Facilitated connections.
FACILITATED CONNECTIONS: HEALTH CARE PROVIDER (2A) AND FAMILY NETWORK PROGRAMS (2B) SUPPORT PARENTS' ACCESS TO GENETIC SERVICES DURING THE PAST TWO GRANT YEARS.
Engage Members of Underserved Communities to Improve Access to Genetics Services
<table>
<thead>
<tr>
<th>Distribution of Materials</th>
<th>Training</th>
<th>Health Screening and Clinic</th>
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<tbody>
<tr>
<td>• Brochures for parents</td>
<td>• 23 adults participated in a training for Marshallese families</td>
<td>• 25 adults participated in health screen</td>
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<tr>
<td>• NBS video</td>
<td>• 53 participated in Marshallese Interpreter Training</td>
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<td>• Early Hearing &amp; Detection Video</td>
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<tr>
<td>• Tip sheet for providers</td>
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Marshallese Community
Feedback on Marshallese Clinic and Community Training

• A culture of trust was apparent at the event.
• Relationships with community partners made a difference.
• Need to expand community partners.
• Families have broad health care needs.
• Need for follow-up and wrap-around services.
• The event was a learning experience for staff attending.
24 Participated in Interpreter Trainings

Majority (73%) of participants improved knowledge at the end of the interpreters’ training.
MORE INTERPRETERS RATED THEY WERE COMFORTABLE OR VERY COMFORTABLE IN INTERPRETING GENETIC CONTENT

Before Training

Uncomfortable: 31%  
Neutral: 31%  
Comfortable: 24%  
Very Comfortable: 14%

After Training

Uncomfortable: 4%  
Neutral: 18%  
Comfortable: 43%  
Very Comfortable: 35%

n=48

*Represents items as uncomfortable or very uncomfortable
Videos in Spanish Completed and Distributed on You-Tube

“Now that they [the videos] are developed, there is a need to figure out the best way to get them in the hands of those that can use them with families.”

- How to prepare for and understand what will happen at your child’s genetic test
- What are chromosomes and genes?
- What can I expect from an appointment at a genetics clinic?
- How to work with an interpreter for a medical visit
- Newborn Screening
Need to Disseminate Information about Videos

STRATEGIES
• Webinars and Presentations could be used to promote the videos
• Additional resources could be included with the videos
• Expanded marketing with promotional materials was recommended
Need to Disseminate Information about Videos

TARGET POPULATION

• Students in the health care professions could be a key to building a culturally competent workforce
• Geneticists and genetic counselors should be a primary target for dissemination
• Family support programs’ relationship[s with families is an advantage for dissemination efforts
Innovative Telehealth Delivery Model

2 Distant Site 9 Originating Sites

Arkansas (5) Oklahoma (3)
Kansas (2) Colorado (1)
**TELEHEALTH CLINIC SERVICES:** # OF PATIENTS FOR WHOM TELEHEALTH MODALITIES FOR GENETICS WERE USED.

In 2022-2023 91% of the patients were from underserved areas.
Facilitate Learning through Sharing Resources and Training
Participants that live in underserved areas

All Participants

TRAINING: # OF INDIVIDUALS PARTICIPATING IN TRAINING

5 HRGN SPONSORED TRAININGS.
Videos (7)  

Web-Based Resources

Pamphlets

Distance Modules
Questions?