



**Midwest Genetics
Network**
Region 4

Midwest Genetics Network

PROVIDER EDUCATION UPDATE

Accomplishments Year One

Establish a Work Group

- Roster of 29 individuals representing 7 states
- Meets every other month
- Guides provider education activities
- Genetics providers, primary care providers, family members, researchers, and public health professionals comprise the membership

Accomplishments Year One

Develop Maintenance of Certification Part 4

- 1st topic was identified
- Sub-workgroup formed
- MOC4 to improve communication of NBS results developed and implemented

Co- Chairs – Sue Berry and Olivia Wenger

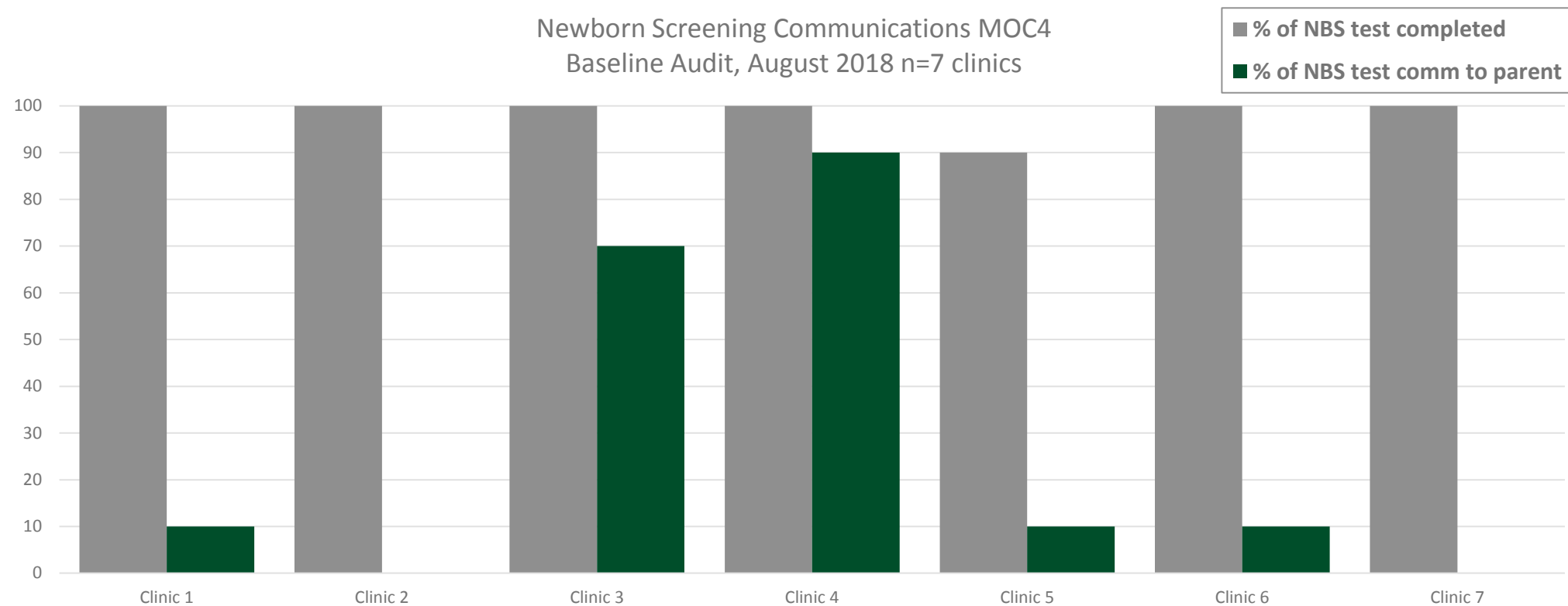
Members - Mimi Behar, Bridget Bucksacker, Caleb Bupp, Kathy Cairns, Amy Gaviglio, Lauren Hitchens, Tami Horzewski, Katy Morgan-Davies, Chuck Oberg, April Studinski, Angie Thompson, Sarah Zoran

Accomplishments Year One

Improving Newborn Screening Communication

- 82 pediatricians from 9 states registered (all 7 Midwest Region states plus ND, SD, and IA)!
- 37 participants at the first LIVE session about the NBS system presented by Amy Gaviglio on September 17th
 - 6 playbacks as of last week
- 2 additional sessions coming up
 - Communicating negative/normal NBS results – Sue Berry and Whitney Thompson will co-present later this month
 - Communication borderline and positive NBS results – Chuck Oberg and family members will co-present in November

Nearly 100% of babies had NBS test but 0% to 90% told the parents the screening results



Questions



Panel Discussion – Communication among families, PCPs, and genetics providers when there is a new diagnosis

Moderator:

- Cindy Cameron

Panelists:

- Latrieva Boston
- Katy Morgan-Davies
- Mimi Behar
- Olivia Wenger

