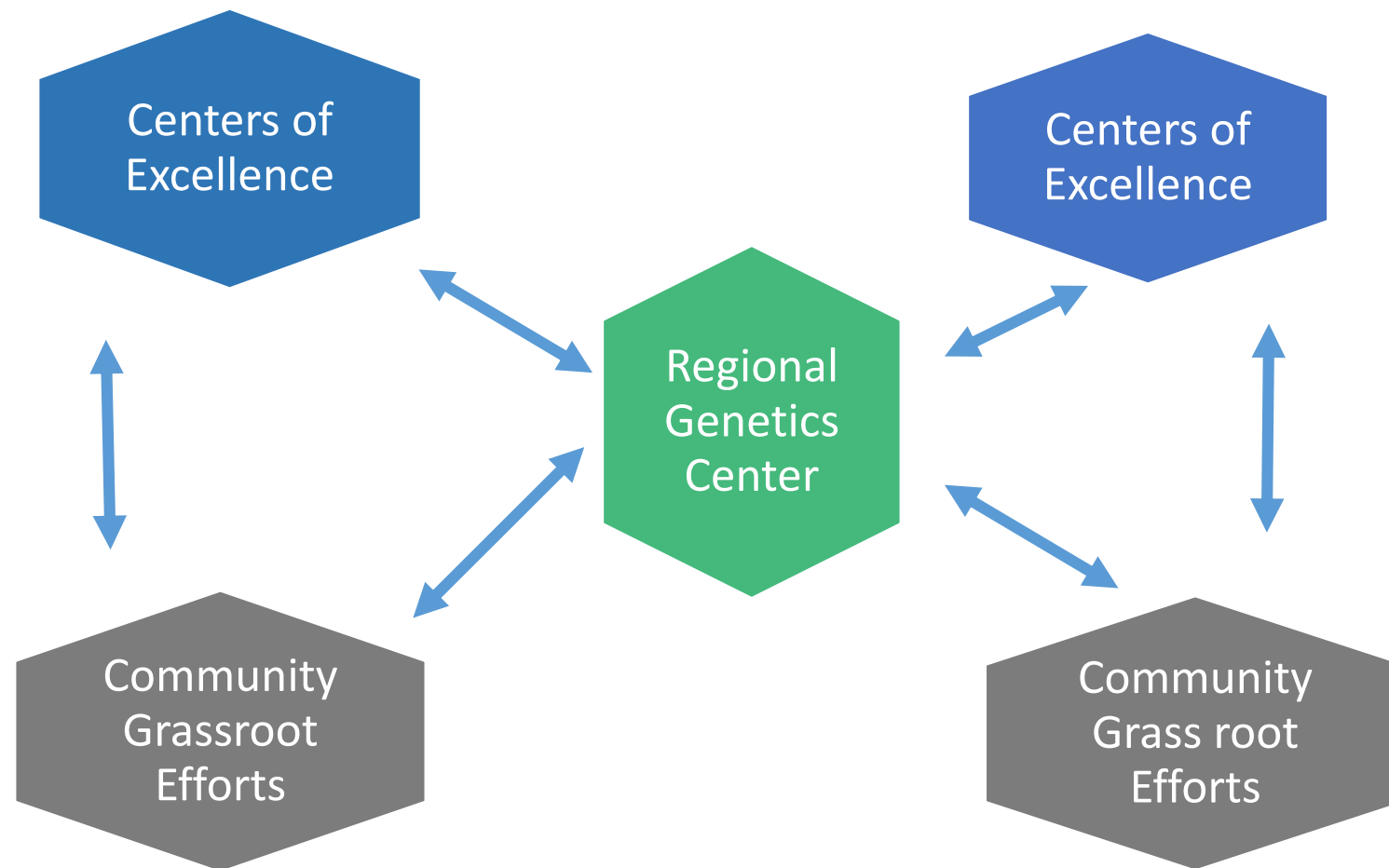


# BEGINNINGS AND ENDINGS

PRESENTED BY BARB JACKSON AND ANAYELI HERRERA MORALES

# ADVISORY BOARD: LISTENING SESSION



Regional Genetics Center: Hub and Spoke Model with a Foundation of Collaboration

# KEY COMPONENTS

- ▶ Life Course Care (genetic services, transition)
- ▶ Workforce Development
- ▶ Education
- ▶ Care Coordination



**Heartland Advisory Board Meeting  
April 29, 2015**

# ADVOCATES

- ▶ Sharon Romelczyk led the visioning questions sessions
- ▶ Reviewed the connections between National, HRSA, ACMG, NGEEN, NCC, and the seven regional collaboratives
- ▶ Reviewed the mission statement, membership, and participation
  - ▶ The Advocate of the Heartland Genetics Services Collaborative is committed to work to improve the health and welfare of individuals with special health care needs and their families. We initiate and support efforts to alleviate problems and improve the quality of life in a patient-centered, community-based comprehensive medical home.
  - ▶ Members of the Advocate Work Group can be individuals, parents or relatives of children with the special health care needs or other concerned participants in this mission.
- ▶ Co-Chairs: Michelle Black & Jeanne Egger



**Heartland Advocate Meeting  
April 30, 2015**

# EARLY HEARING DETECTION AND INTERVENTION (EHDI)

- ▶ Workshop on Wednesday was a great opportunity to come together and discuss:
  - ▶ **Border Babies Exchange**
  - ▶ **Long Term Follow-Up State Approaches**
  - ▶ **Long Term Follow-Up Calculations: CDC vs States Data Reporting**
  - ▶ **Cytomegalovirus (CMV) Screening: Conference in Salt Lake City, UT on September 2014**
- ▶ **Dr. Karl White, National Center for Hearing Assessment and Management Representative**
- ▶ **Work group would like to continue having this EHDI exchange workshop in the future**



**Heartland EHDl Meeting  
April 29, 2015**



# Newborn Screening

- ▶ SCID updates
  - ▶ 3/8 states are currently screening
  - ▶ 5/8 are somewhere in the process
- ▶ LSD update from Missouri
- ▶ Emergency Preparedness Update
  - ▶ AR/MO 2014 drill was “the best, fastest and smoothest drill we have ever conducted in the Heartland (This was Drill #16)”
- ▶ COIIN Update from Iowa
  - ▶ Working to improve timeliness in the state of Iowa and take lessons learned into the Heartland states
  - ▶ intend to “mimic” the process for the Heartland states.

NBS



# CLINICAL SERVICES

- ▶ Brain storming session for regional model
- ▶ Will continue working on the current projects for the next two years
  - ▶ Hispanic Access
  - ▶ Individualized Health Plan
  - ▶ Healthcare Transition
  - ▶ Family Health History
  - ▶ Telemedicine
  - ▶ Medical Home
  - ▶ Time Study Around Payer Issues\*



# HEARTLAND GENETICS SERVICES COLLABORATIVE *THANK YOU!*

- ▶ Planning Committee:
  - ▶ Liz Abbey (EHDI)
  - ▶ Jo Ann Bolick (Newborn Screening)
  - ▶ Carol Johnson (Clinical Services)
  - ▶ Jeremy Penn (Advisory Board)
  - ▶ Mark Smith (Advocate)