



## Emerging Regional Issues

Putting into context what the  
HRCC is doing

### 1. Participation in HRCC

- "100% participation from clinical genetics centers and NBS programs"
- Advocates
- Genetic counselors



## 2. Quality clinical genetics services in the region

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- Medical geneticists by state
  - AR (4)
  - OK (3)
  - KS (2)
  - NE (4)
  - IA (4)
  - SD (2)
  - ND (1)
  - MO (7)



## Clinical Geneticists (MD's)

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### United States

- ~ 1000 clinical geneticists
- Average 0.5 FTE seeing patients
- 1/300,000 Americans
  - 3.5 / million
- Ratio of geneticist to children
  - 1:5,748,082
- 0.15% of all MD physicians



## Genetic Counselors

United States

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- ~ 1800 CGC's
- 1/170,000 Americans
  - 6 / million
- Mean national salary \$54,000



## Workforce Study

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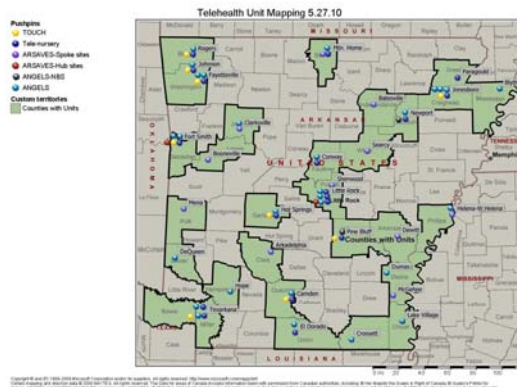
- Global deficiency in health care providers in clinical genetics
- Most critical shortage for metabolic geneticists
- Current training output is at a rate that is not keeping up with turnover

## Enhancing clinical genetic services

- Efforts to increase current workforce
  - Training
  - Recruitment ( 4 open spots in AR)
  - Technology
  - Different ways to deliver services
  - Emergency preparedness
  - Evaluation (GSA)

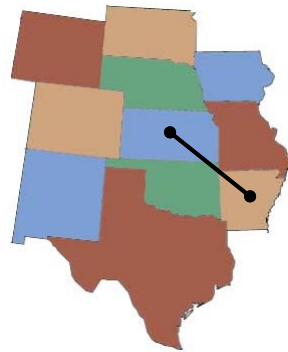
## Outreach

- Telemedicine to >35 sites



## Outreach

- Wichita
  - 1 genetic counselor
  - UAMS physician support (telemed)



## 3. Promote Genetics Education

- All levels
- Resource sharing
- Develop modular programs
  - National
  - Organizational
  - Regional
  - State
  - Institution



## 4. Transition Services for Youth with SHCNs

- 90% of YSHCN reach their 21<sup>st</sup> birthday
- 45% of YSHCN lack access to a physician familiar with their health condition
- 30% of all youth 18-24 years of age lack a payment source for health care
- 40% YSHCN demonstrate ER use annually (vs 25% of 'typical' youth)
- YSCHN experience increased school interruptions



## Transition Areas

- Health Care
  - Health promotion and preventive care
  - Specialized care
  - Prevention of secondary disability
- School to Work
  - Education
  - Vocational readiness
  - Career choice
- Dependency to Independence
  - Housing
  - Adaptive living skills
    - Dressing/grooming
    - Food purchasing and preparation
    - Budgeting



## Medical Genetics in Transition

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- These are 'our kids'
- Role of medical genetics
  - Participant in MD team
  - Consultant
  - Direct provision of services
  - Gap-filling services



## 5. Response to NBS initiatives

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- LTFU
- QA
- Addition / expansion of core panel



## 6. Changes in HRCC

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- Next 2 years
  - Staff
  - Grant structure
- 5 year competitive renewal
  - Federal guidance
  - Regional specifics



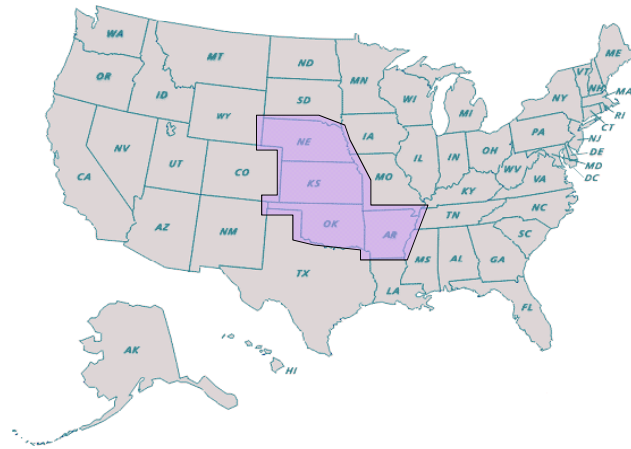
## 7. Networking / collaboration

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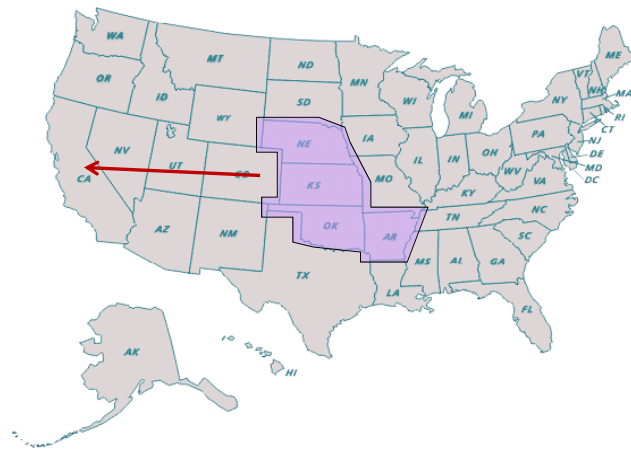
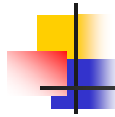
- GPGSN and beyond
  - MAGEC



# Mid-America Genetics Education Consortium



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## 8. Genetics and the Greater Community

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- NCC (HRSA/GSB)
- Professional organizations (ACMG / NSGC/NCPEG/ Genetic Alliance)
- LEND