



**Midwest Genetics
Network**
Region 4

Midwest Genetics Network

ANNUAL MEETING

OCTOBER 1-2, 2019

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Workgroup Report Out: Health Equity- Interpreter Training

Develop a plan for a train the trainer event and distribution model in the Midwest Region

Determined training teams: Genetic Counselor/Health Care Interpreter team.

Relationship Building/Outreach:

- Language services at hospitals
- State Genetic Counseling organizations
- Professional organizations for health care interpreters



Workgroup Report Out: Health Equity- Interpreter Training

Develop a plan for a train the trainer event and distribution model in the Midwest Region

Support/Sustainability :

- Looks at sustainable models such as virtual/web-based options
- Funding for train the trainer and regional spread in next funding cycle
- Include health care interpreters in planning and implementation
- Research- Requirements for interpreters, CEUs, how many interpreters, etc.

Workgroup Report Out: Health Equity- Regional Resources



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Develop a plan to compile and document health equity experts across the region in states and communities for information, referral, and support for those providing genetic services.

Most helpful resource types :

- Practical
- Accessible
- Free or freely accessible
- Best Practices
- Models to replicate that address health equity
- Data (how well or how poorly are we doing?)
- Role of legislature/ Advocacy



Workgroup Report Out: Health Equity- Regional Resources

Develop a plan to compile and document health equity experts across the region in states and communities for information, referral, and support for those providing genetic services.

Partners/Resources:

- State public health programs
 - Title V
 - Maternal Child health programs
- Professional organizations for genetic service providers
- Family Voices
- Family to Family Health Information Centers
- Health Equity Researchers
- LEND
- Community partners



Workgroup Report Out: Telegenetics

- Telegenetics Trainings
 - Include support staff training
- Grants
 - Shift focus to outcomes projects
 - Continue to support pilot/infrastructure building projects
- Workgroup Meetings
 - Function as a resource for each other
 - Project work
 - Look at how we might address nuances of billing from center to center to provide proof of value for services and sustainability



Workgroup Report Out: Provider Education

- MOC4 Continuation
 - Hearing Screening (Similar to Bloodspot screening)
 - Appropriate follow up
 - Genetic testing
 - Physicians Following current guidelines for caring for patients with Genetic Disorders
 - Caring for adults with disabilities
 - Transition
 - Educating Adult providers regarding the disorders
- ECHO Webinars
 - Use Tele-mentoring process “ECHO-Light”
 - Add LEND Genetic Module for genetic provider education
 - Do a Case Study of a person with an unknown genetic disorder. What does the care look like?
- New Provider Education Initiatives
 - Residency/Medical School Education Opportunities (train Nurses, PA, Etc.)
 - Communication regarding “What a family needs to know” resources written for families throughout their care (timing is everything!)
 - **Empower** providers on access to ready genetic resources for genetics learning CMEs
- Continuing Medical Education (CMEs)
 - Basic Genetics 101 (Use interpreter training)
 - Consumer Initiated Genetic Testing Training
 - New Genetic Testing Information



Workgroup Report Out: Plain Communities

- Presentation from DDC Clinic – Center for Special Needs Children
Supplemental Newborn Screening Panel for Amish
- Discussion on Provider Education
How do we reach providers who may serve Amish patients?
Which providers should we be targeting?
What systems can be put in place for follow-up and care coordination?
- Patient Engagement
Training/Educational Curriculum

Establish two workgroups: Provider Education, Family Engagement

Closing Plenary & Priority Wall

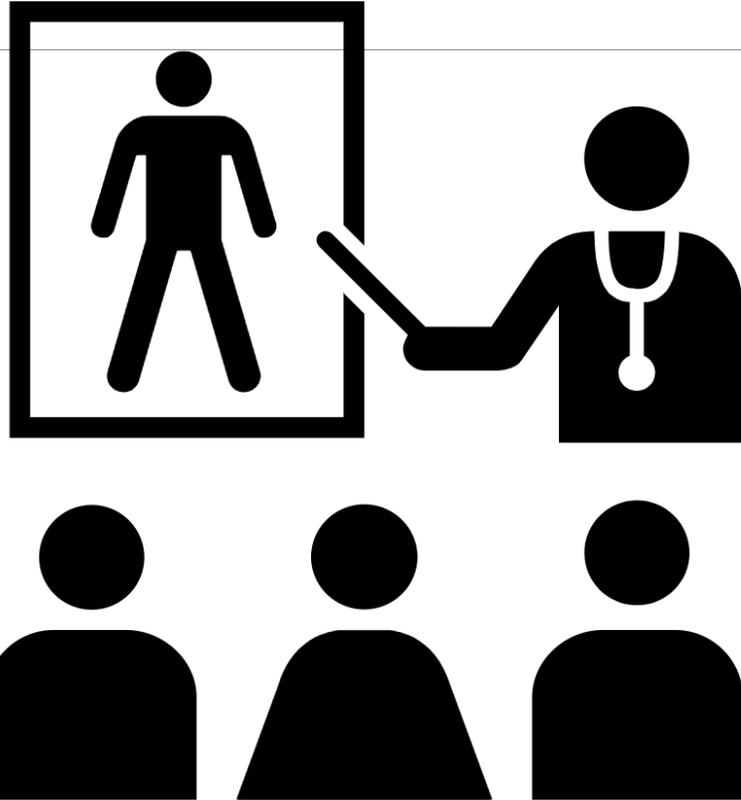
What emerging projects, priorities, or partners should the Midwest Genetic Network continue to work on or begin work on in the next funding cycle?

Telegenetics



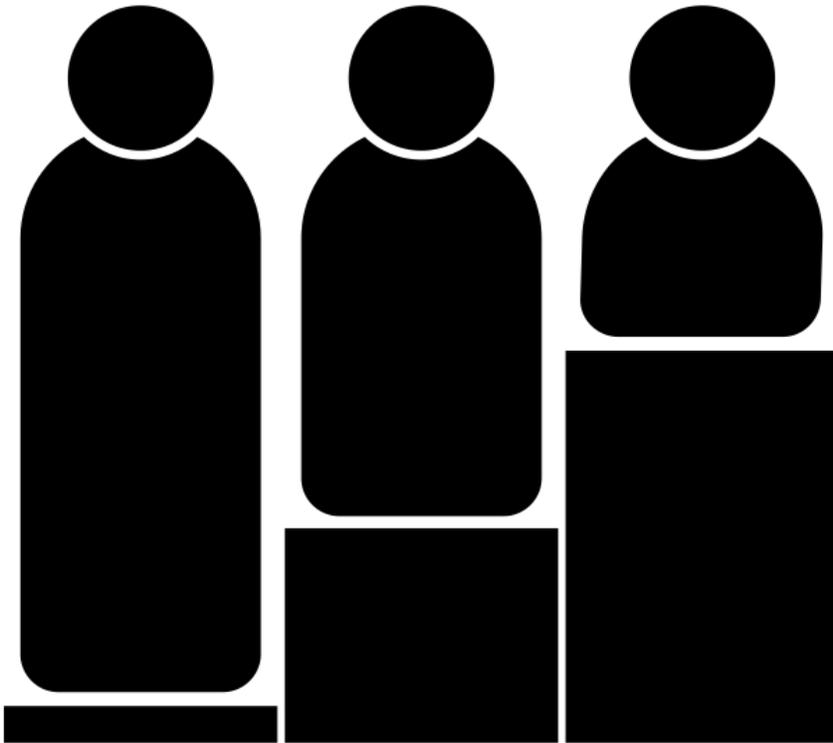
- Strategies for coverage
 - Different team members
 - Tip sheet or tool kit for billing/ reimbursement
- More family telehealth videos for non-pediatrics genetic services
- Links to resources
- More advance notice of future trainings
- Feedback from referring providers whose patients had used telemedicine

Provider Education



- Caring for adults with disabilities
- Educate health department nurses-Children’s Special Health Care Services
- Expand “provider” definition and work with non-genetics providers (Peds nurses, Pas, FPs)
- Support HR 3235 access to genetic counseling
- Case report forms; New steps definitions
- Universal provider ACT sheets
- Use available technology (EMR & live links to resources)
- Triage/ collaborative processes
- VALUE of genetic services (why free counseling not best practice)
- Strategies to improve access to basic genetic testing for PCPs (working with insurance, specific to states)

Health Equity



- Incorporating cultural agility more broadly
- Interpreter training
 - How to bring to our/ other institutions
 - Invite genetic providers to help develop/ review curriculum
 - Cover non-pediatric indications
 - Differences in cultural meaning/ interpretation of genetics
- Access to genetic testing outside of the medical genetics encounters (direct to consumer, primary care)
- A LOT we are not addressing. What is broader strategy for reaching underserved?
- How to include social determinants of health

Family Engagement



- Collaboration
 - Use technological resources to connect
 - Inter-university
 - Inter-health systems (genetics not only academic)
- Recruiting
 - More family members
 - Diverse families
- Advocacy for families care for ADULTS with disabilities
- Personal invitations to case managers to attend MGN