



**Midwest Genetics  
Network**  
Region 4

# Midwest Genetics Network

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**ANNUAL MEETING**

**OCTOBER 1-2, 2019**

*"This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number UH7MC30775, Midwest Genetics Network for \$1,800,000 (0% financed with nongovernmental sources). This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government."*



# Agenda Overview

## Tuesday, October 1, 2019

8:30 am – 9 am	Registration & Breakfast	Commons
9 am – 12 pm	Plenary Sessions	B106/B107
12 pm – 1pm	Lunch	Atrium
1 pm – 2pm	Plenary Session	B106/B107
2 pm – 4 pm	Workgroup Meetings	*See Agenda
4 pm	Adjourn	
5 pm	Welcome Dinner Reception	Atrium

## Wednesday, October 2, 2019

8 am – 9 am	Family Representative Breakfast	Four Seasons
8:30 am – 9 am	Breakfast	Commons
9 am – 12 pm	Plenary Sessions	B106/B107
12 pm	Adjourn	



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# The MPHI Team





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# What is the MGN?

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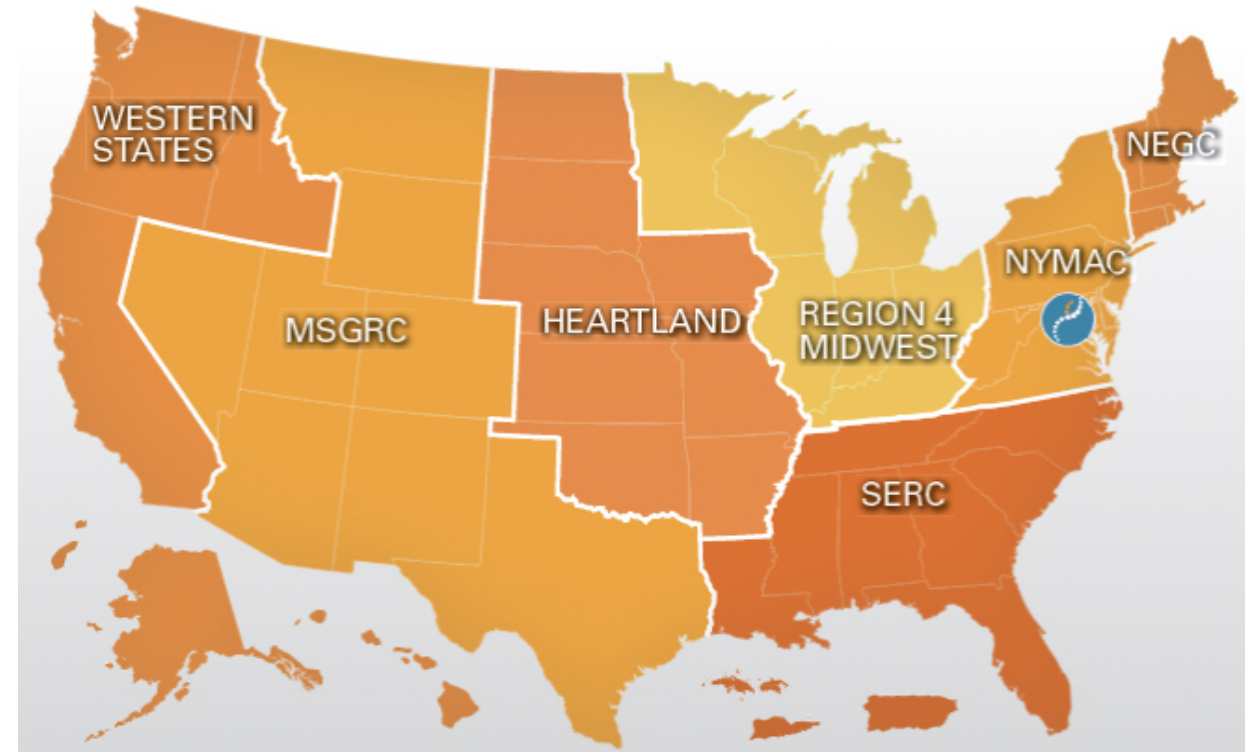
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# Midwest Genetics Network

A seven state region within a national network of organizational and individual stakeholders *working to improve access to genetics services* for underserved populations

Funded by Health Services and Resources Administration, Maternal and Child Health Bureau, Genetic Services Branch





# Regional Genetics Networks

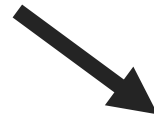
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The purpose of the RGNs is to:

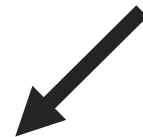
- 1) Link medically underserved populations (based on poverty, rural geographic location, and/or populations that experience health disparities) to genetic services;
- 2) Implement evidence-based innovative models of telehealth and/or telemedicine with a focus on clinical genetics outreach; and
- 3) Provide resources to genetic service providers, public health officials and families.

# Regional Activities

Education and Relationship  
Building between Genetics  
and Primary Care



Training and Infrastructure  
Support for Telehealth



**Increased Access for  
Underserved Persons**

Engagement of partners who work  
with underserved communities





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# Our People

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- **Our Experts**

- Patients and Families
- Clinical Genetics Providers
- Public Health
- Primary Care Providers

- **MPHI**

- The team that supports the experts





# Our Structure

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**Health Equity:** Oversee implementation of a regional strategy to ensure that health equity efforts are supported and culturally appropriate strategies to engage underserved populations are developed.

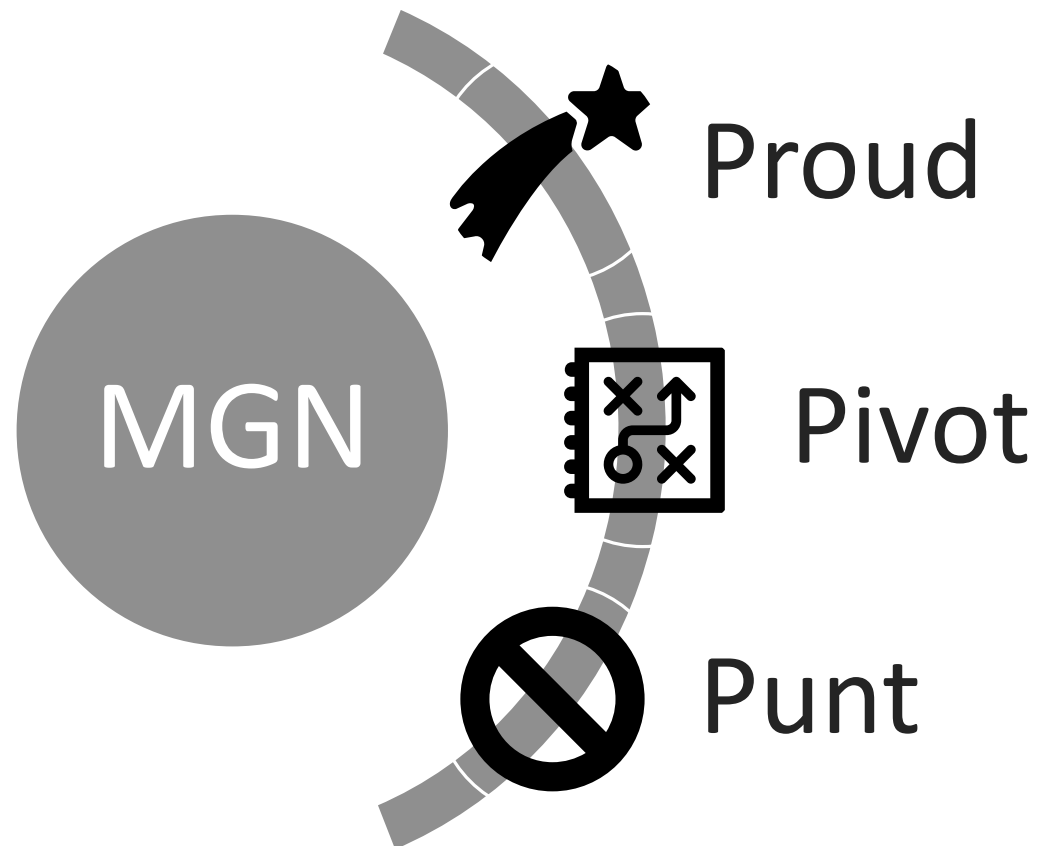
**Provider Education:** Develop MOC4 modules to improve provider adherence to genetic clinical guidelines. Share the modules with AAP chapters across the MGN states, other RGNs and the NCC.

**Telegenetics:** Develop a strategy to increase the use of telegenetics by providing trainings for clinicians, facilitating learning communities, and developing an online training geared toward patients and their families.



# Funding Cycle Review

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# What's New?

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**HRSA 20-046** - To improve health equity and health outcomes in individuals with genetic conditions (including congenital and metabolic disorders), reduce morbidity and mortality caused by genetic conditions, and strengthen and improve the quality of coordinated follow-up and treatment for comprehensive genetic services.



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# MGN Priority Wall

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

Responses will be clustered around three themes:

- Family Engagement
- Provider Education
- Telegenetics
- Health Equity

# NCC

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# NGEFC

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# Workgroup Updates

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# Health Equity

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Identify and engage partners who work with underserved communities

## **Progress to date:**

- Established a Plain Communities Workgroup.
- Collaborated with New Leaf Clinic (OH) to sponsor a family/provider meeting for GM3 Synthase Deficiency in May, 2019
- Awarded a grant to the Waisman Center (WI) to explore the use of telehealth in a WI plain community
- Awarded a grant to DDC Clinic (OH) to sponsor three disease-specific meetings, and a series of Mothers' Support Groups (from November 2019-April 2020)



# Health Equity

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## **Upcoming activities:**

- Develop an Advocacy Training for families caring for children with special health care needs
- Collaborate with the Telegenetics Workgroup to pilot the use of telehealth with Plain Populations
- Financially support clinics to sponsor educational activities with families and providers
- Collaborate with Provider Education Workgroup to develop educational materials for providers who work with plain populations



# Health Equity

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- Conducted a 6-hour workshop for interpreters to learn to work in the field of pediatric genetics.
- The workshop introduced:
  - Basic Concepts in Genetics
  - What to expect in a pediatric genetic consult
  - The reasons and results of genetic testing
- 50 medical interpreters were trained



# Health Equity

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## Today's Workgroup Meeting:

- Develop a plan for a train the trainer event and distribution model in the Midwest Region
  - Target audience
  - Attendance
  - Location
  - Fidelity
- 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.



# Provider Education Project

**Goal:** Develop educational materials and/or opportunities for primary care providers that will result in **the right people** (patients/families, primary care providers, geneticists) **talking to each other more often and with better effect**

**Strategy:** Develop and implement MOC4 modules focused on genetics care for PCPs

## Progress:

NBS  
Communication  
Cohort 1

**COMPLETED**

- 92 Providers  
- 27 clinics  
across 9 states

NBS  
Communication  
Cohort 2

**ON GOING**

- 55 providers  
- >40 clinics  
across 12 states

Referral and testing  
for ASD, DD, and  
dysmorphology

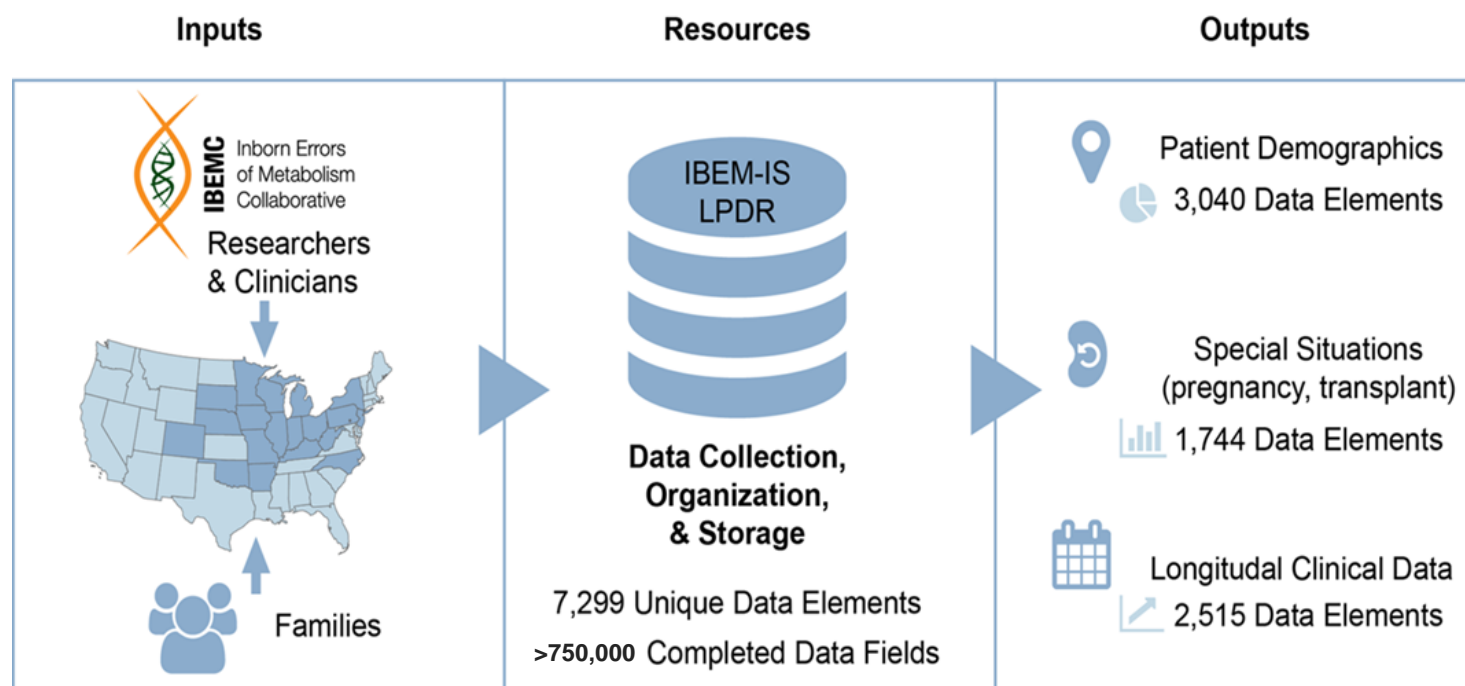
**UNDER  
DEVELOPMENT**

Will have  
national  
recruitment



# Long-Term Follow-Up Project

Increase the racial and ethnic diversity of patients included in the IBEM long term follow up data, beginning with MGN states and including state from other regions





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# Long-Term Follow-Up Project

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## Progress

42 new subjects were enrolled from 2 centers

14 (33%) of these new subjects were racial and/or ethnic minorities



# Telehealth Project

Provide education for families and providers to increase their comfort level and utilization of telehealth services

Share the family education materials with other regional genetics networks

- Telegenetics Trainings
  - 29 Genetic Counselors
  - 5 Geneticists
  - 2 Students
  - 2 Dieticians
  - 1 Genetic Counseling Assistant
- Telegenetics Grants
  - 6 grants 2018-2019 cycle
  - 6 grants 2019-2020 cycle



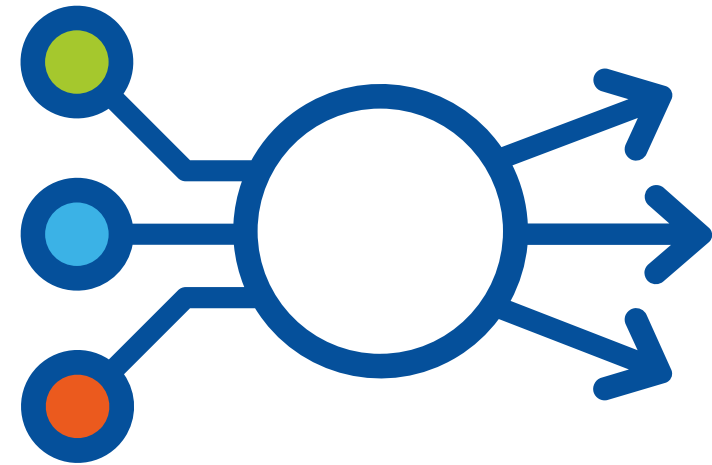
*Telegenetics Grant Recipients 2018 and 2019 Cycles*



# Telehealth Project

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- 273 Patients seen across 120 zip codes in Year 2  
*based on data reported to MGN to date*
- 92 zip codes medically underserved areas & populations
- 5 MGN states; 2 outside MGN







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# Telehealth Video

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<https://midwestgenetics.org/resources/telemedicine-resources/>



# Lunch

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# Telegenetics Panel

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Jessica Scott Schwoerer

Samantha Cassisi

Sandy Prucka

Sara Zoran