



**Midwest Genetics  
Network**  
Region 4

# Midwest Genetics Network

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REGIONAL MEETING

OCTOBER 1-2, 2018

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# What is the MGN?

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# Midwest Genetics Network

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One of 7 regions 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





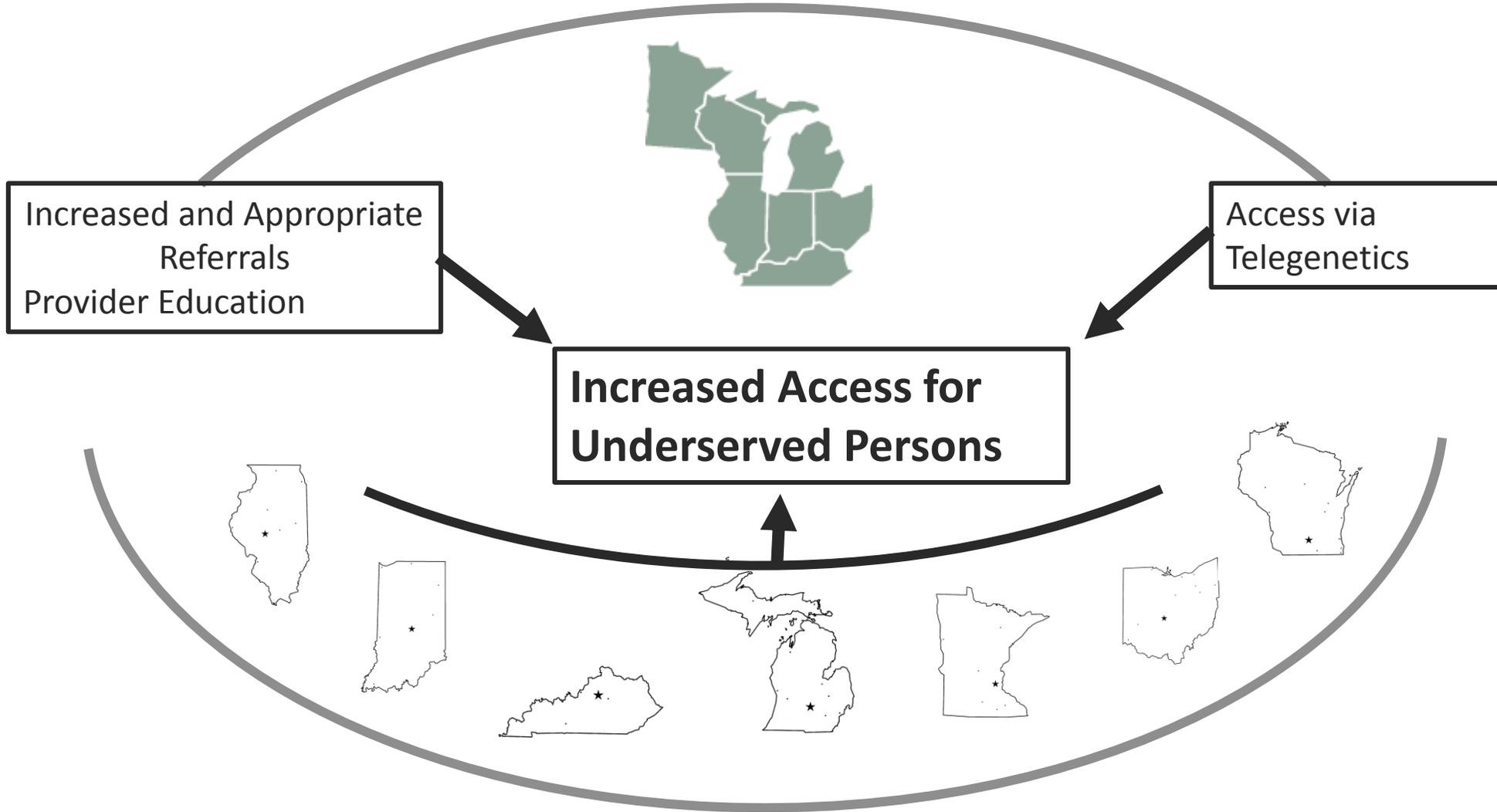
# Regional Genetics Networks

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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





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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.



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# Our Vision

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To impact access to genetic services for traditionally underserved populations within our own region and beyond



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# What Have We Accomplished?

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# Health Equity Project

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To support MGN states to

- Identify underserved populations
- Engage community organizations and patients and their families representing underserved communities
- Create state-specific strategies to improve access to genetic services

## **Progress**

Working with the Hispanic Community at the 16<sup>th</sup> Street Community Health Centers,  
Milwaukee, Wisconsin

# Telehealth Project

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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

## **Progress**

Telehealth training for providers

Awards to support expansion of telehealth services

Videos for families and patients on telehealth



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# Provider Education Project

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Develop educational materials 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

Work with state chapters of national organizations to pilot our model within one state, expand to states; across our region, and promote national use

## **Progress**

MOC4 created; implementation initiated



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# Long-Term Follow-Up Project

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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

## **Progress**

27 new subjects were enrolled from 2 centers

10 (37%) of these new subjects were racial and/or ethnic minorities

1 clinic utilized translation services

1 additional clinic preparing to re-start data entry

# What's New?

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# Partnerships

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The right people at the right time to achieve our  
vision

# Why Are Populations Underserved?

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Geographic location

Family resources

Lack of sub-specialists and where they are located



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# Working with Plain Communities

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Of the ten states with the highest Plain population, 6 are in our region. Minnesota is #11 on the list

Approximately 58% of Plain People in the U.S. live in our region, or about 180,000. Ohio has over 70,000 Amish

Because of the shallow gene pool, Plain Communities experience a higher than average incidence of metabolic disorders and other heritable conditions

Some Plain Communities do not accept Medicaid or other forms of insurance, which makes it difficult to afford metabolic formula

Plain People live in rural areas and some still use buggies for transportation, making it extremely difficult to access a genetic specialist

The 2019 Amish Conference will focus on Health and Well-Being in Amish Society and will include a plenary on Engaging Amish and Plain Communities in Addressing Health Disparities



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# Engaging Public Health

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HRSA Priority - Implementing new conditions on the recommended uniform screening panel (RUSP)

State newborn screening labs are experiencing barriers to implementing screening when new conditions are added, which could delay diagnosis

State newborn screening programs increasingly are planning for longer-term follow-up based on the nature of new conditions added

Models for connecting families with resources an option



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# Housekeeping

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Breakout rooms

Workgroup assignments

Reception

Breakfast and Lunch - Atrium

Patient/Family Breakfast

Engaging Plain Communities Breakfast

Reimbursement