



**Midwest Genetics
Network**

Region 4

MGN 2020 RFP CYCLE

Goals & Objectives:

MGN's overall goal is improve health equity and health outcomes in individuals with genetic conditions and to improve the quality of coordinated and comprehensive services to children with such conditions and their families by supporting an infrastructure to improve access to genetic services, providing training and education to health care professionals and supporting families.

Program objectives for the 2020-2024 funding cycle include: improving access to genetic services, increasing the utilization of telemedicine, and educating and engaging stakeholders.

Funding Amount: Up to **\$10,000**

1 Year Cycle: **November 1, 2020 – October 31, 2021**

7 applications Received; 4 Applications funded



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Project #1: Telemedicine for Genetics Counseling in light of the SARS-CoV-2 Pandemic

Organization: Genomic Medicine Department at Children's Hospitals Minnesota

State: Minnesota

Statement of Impact: Our goal is to further integrate telemedicine into our outpatient genetics clinical setting by developing a hybrid clinic model to see patients who require an in-person Genetics Clinic evaluation at Children's Minnesota (MN). In order to minimize exposures to our at-risk patients and between clinical staff while providing high quality patient care in light of the current SARS-CoV-2 pandemic, patients and their families can meet with a Genetics MD/APRN for a face-to-face visit and also meet with a Genetic Counselor (GC) at the same time via telemedicine in a hybrid model. We expect the immediate and long-term effects will improve patient access to comprehensive Genetics/Genetic Counseling services.



Tweet about it: The Genetics team at Children's MN is very excited to share that we are expanding the use of telemedicine in our outpatient clinics. Families now have improved access to comprehensive Genetics and Genetic Counseling services and can get the care they need more easily!

Project #2: Educating Amish Parents of Newborn Infants About Rare Genetic Conditions



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Organization: DDC Clinic, Center for Special Needs Children

State: Ohio

Statement of Impact: DDC Clinic makes available to Plain Community settlements an Amish genetic panel test which can diagnose 160 rare conditions using one blood sample. This test is available to families and physicians and is offered to families of newborn infants at the Middlefield Care Center/Birthing Center. Families of newborn infants will receive education and treatment, if needed, about these rare diseases.

Tweet about it: DDC Clinic offers a genetic test for 160 rare conditions common in the Plain Communities using one blood sample. This test is offered to Amish families at the Middlefield Birthing Center at no charge. DDC Clinic provides treatment to affected infants/children and education to families about these 160 rare conditions.



Project #3: Cardiovascular Genetics Education & Awareness



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Organization: Bethesda North Hospital at TriHealth

State: Ohio

Statement of Impact: TriHealth is in the process of establishing a specialized cardiovascular (CV) genetics clinic. Two goals in establishing this clinic are 1) produce patient education materials to aid in increasing the uptake of genetic counseling services among patients with hereditary cardiovascular conditions and 2) increase awareness of genetic services among stakeholders such as non-genetics providers.



Tweet about it: 1 in 200 people have a hereditary heart condition. Increasing access to CV genetic services is important at #TriHealth. Providing patient and provider education with videos and written materials increases referral efficiency and sets patient expectations for a GC appointment.



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Project #4: Resources for Families of Children with Genetic Conditions

Organization: Family Voices Indiana

State: Indiana

Statement of Impact: Funding from the Midwest Genetics Network will allow Family Voices Indiana to host focus groups, offer training and create a telemedicine resource guide so that families of children with genetic conditions can understand, access and successfully navigate telemedicine and are aware of the latest advances in genetic testing, treatment, and support.



Tweet about it: #Resource for families of children with genetic conditions-- #telemedicine has been our lifeline! Click for your FREE guide to services, thanks to @Region4Genetics *insert link* #FamilyVoices #MidwestGeneticsNetwork