Work Plan Review – Project Period 6/1/2020 – 5/31/2024

Goal: 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

HRSA Objective	Activity	Year	Status	Pivot, Pause, Pursue
1. By May 2024, facilitate connections to genetic services for at least 2,000 individuals or families with or at risk for genetic conditions, within the geographic region served by the RGN	A. Provide grant funding to clinics to increase adherence to newborn screening (NBS) and follow-up visits with geneticists in Plain Communities	1-3	**Innovation awards offered annually. 2021 awards to be made on or before September 15, 2021. Four awards granted in 2020 totaling $32,750:** • **Children's Hospitals Minnesota – developed and implemented a hybrid model that integrates telemedicine into the outpatient genetics clinical setting ($9800)** • **The DDC Clinic – Center for Special Needs Children in Ohio educates Amish parents of newborn infants about rare genetic conditions and offers an Amish Genetic Disease NBS panel ($10,000)** • **Bethesda North Hospital at TriHealth (Good Samaritan Hospital of Cincinnati, OH) established a specialized cardiovascular genetics clinic and educates patients and providers via video and**	

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			written materials to increase referral efficacy and shape patient expectations ($6184) - **Family Voices of Indiana developed a telehealth resource guide in both English and Spanish for families of children with genetic conditions ($6766)**	
	B. Implement pilot project to link PKU patients lost to follow-up to genetic services, expansion of pilot to other states and regions	1-4	**Identified PKU patients who were lost to follow-up in MI. Developed a survey and accompanying informational materials to send to lost to follow-up patients. Began identifying potential states for project expansion**	
	C. Sponsor *Interpreter in Genetics* training in underserved communities	1-4	**MGN staff participates in NCC workgroup; trainings scheduled for 2021-2022**	
	D. Increase engagement of genetic service providers within MGN	1-4	**96 newly engaged members in workgroups, trainings, and annual meeting attendees (not including ECHO 101 sessions)**	
	E. Create Patient and Family Council	1-4	**The Patient and Family Council was established and has 31 members. The PFC meets monthly**	
	F. Offer small grant funds to Family-to-Family organizations in the region	1-3	**See above Innovation awards (Family Voices Indiana $6766)**	
	Activities 3B, 3C, 3D, and 4B also contribute to meeting this objective			

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2. By May 2024, increase to at least 33% of individuals who are medically underserved, with or at risk for genetic conditions, served by each RGN	A. Coordinate Plain Communities Workgroup to facilitate collaborations among providers working with Plain Communities	1-4	**Four (4) Community of Practice forums were offered in Year 1. Three (3) are scheduled for Year 2. MGN is a member of Plain Communities Health Consortium and staff participate in monthly meetings**	
	B. Provide Family Advocacy Training to parents of CYSHCN in underserved communities	1-4	**Curriculum has been developed; pilot has been delayed due to COVID**	
3. By May 2024, increase by 20% the number of health care providers receiving education or training through the RGN	A. Initiate ECHO in MGN region	1	**Established dedicated ECHO staff team, completed intensive ECHO Institute training, finalized user agreements, online document library and hub access. Created MGN documents for ECHO series initiation, communication and marketing documents which include ECHO Road Map, Informational PPT presentation and FAQ document. Rolled out MGN ECHO 101 – Access to Care series in June 2021**	
	B. Develop a data aggregation hub for Maintenance of Certification Part 4 (MOC4) participants	1	**Data aggregation hub created; data collected for ASD/DD CEQI Cohort 1**	
	C. Offer MOC4 modules nationally	1-4	**ASD/DD CEQI project offered nationally. 37 participants from 12 different states registered for**	

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			MOC4 credit. MGN will offer additional MOC4 modules including new cohorts of the NBS Communication and the ASD/Dysmorphology projects. MGN will develop educational offering around Screening and Referral for Familial Hypercholesterolemia	
	D. Implement process to offer MOC2 and CME for current and newly developed MGN resources	1-4	**Obtained approval from MN Medical Association to offer ASD/DD Project for CME/MOC2 credit**	
	Activity 1C also contributes to meeting this objective			
4. By May 2024, increase by 20% the number of individuals with or at risk for genetic conditions, receiving genetic services through telemedicine visits	A. Coordinate monthly Telegenetic Workgroup meetings to facilitate networking and learning and identify projects of interest	1-4	**Small groups to be established as projects are identified; learning opportunities to be offered through an annual telegenetics ECHO series**	
	B. Provide grant funding to organizations seeking to increase capacity and use telegenetics	1-3	**One 2020-21 Innovation Award Children’s Hospital MN $9800**	
	C. Provide telegenetics trainings to genetic counselors, students, and clinicians	1-4	**Telegenetics 101 training needs to be revised**	
5. By May 2024, increase by 20% the number of RGN resources accessed	A. Develop and implement a dissemination strategy for MGN resources	1-4	**A comprehensive dissemination strategy will be developed; currently MGN resources are marketed via the MGN eNewsletter and website**	

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	B. Develop and implement social media strategy	1-4	**Under development and beginning implementation with the assistance of Piper & Gold**	
	C. Maintain & monitor MGN's website	1-4	**In progress. Student Intern will update clinical services directory**	
	D. Maintain connection with AIGCC Clinical Services Directory & Resource Repository	1-4	**MGN staff attend AIGCC/NCC national workgroup meetings; will be contacting clinics to gather clinic information and populate the resource repository**	
	E. Conduct audit of resources developed for patients and families	1	**Audit completed and used to inform current work for the PFC; a resource dissemination plan will be created and implemented**	
	F. Determine ways to disseminate with MGN stakeholders and partners	1		
	G. Update and/or create resources for patients and families to fill gaps identified by audit	1-4	**The PFC is updating the Journey through Diagnosis guide into a mobile app; also creating list of vetted resources**	