



# **Final Evaluation Report**

**June 2017 through May 2020**

# I. Heartland Regional Genetics Network



## Goal of HRGN

In June 2017, the Heartland Regional Genetics Network (HRGN) was awarded a three-year grant from the Health Resources and Service Administration (HRSA). The goal of the HRGN is to expand capacity to improve access to pediatric, metabolic and adult genetic services, targeting medically underserved populations. Underserved populations were defined by disparities in geography, socioeconomic status, and race/ethnic groups in the Heartland region. To accomplish this goal, the project proposed four objectives:

1. Create new pathways to improve access to genetics services by engaging and integrating primary care, home visitors and family support organizations;
2. Improve the quality of care for patients and families accessing genetics services;
3. Implement innovative telehealth delivery models of clinical genetic services; and
4. Provide resources to genetic service providers, public health officials, and families.

Underlying each of these objectives was efforts to engage underserved communities by strengthening relationships with the Marshallese, Hispanic, and Native American communities in the region. Additionally, HRGN was committed to foster inter-regional collaborations and disseminate the results through multiple avenues.

## II. HRGN Evaluation Findings

The purpose of this report is to provide a summary of evaluation findings regarding the HRGN implementation of program activities, its success in accomplishing program outcomes, and performance on HRSA outcome performance measures. A multi-method approach, including qualitative and quantitative methodologies, was used to help inform a continuous improvement process. To date, the emphasis of the evaluation has been tracking the implementation of the project and collecting outcome performance data. Qualitative approaches were used to further explore the impact of the project. Built into the evaluation process was the ongoing review of evaluation data to inform program improvement through reflection and action planning. This report includes a summary of project activities and outcomes throughout the implementation of the three-year grant cycle from June 2017 through May 2020.

## New Pathways to Improve Access to Genetics Services

### IMPLEMENTATION SUMMARY

#### Partnership Trio Model

One of the project's core implementation strategies was to implement a Partnership Trio Model, which included a partnership with non-genetics providers (i.e., primary care providers), family/parent support network staff, and genetic providers. The goal was to increase families' access to genetic services by increasing the capacity of non-genetic providers to support families'

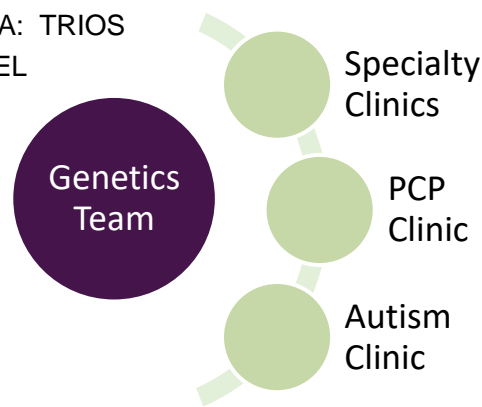
early access to genetic tests in consultation with a genetic provider, as needed. Targeted practices across multiple states were contacted to determine interest in the project during the model conceptualization phase, and seven of the eight states expressed interest in participating.

Twelve sites across six HRGN states participated in introductory meetings to determine interest and feasibility of adopting this model. Of these, three decided to participate in training to gain more information on the model. As a result of this work, one health system, Site A, adopted a modified version of the Partnership Trio Model in six specialty clinics and one pediatric practice. This section will describe the adapted model at Site A, and lessons learned about the implementation processes including its successes, encountered barriers, and lessons learned.

**Implementation with PCP.** Site A is a health care system in the Midwest with hospitals and clinics at multiple sites in three states. Staff at Site A initially were introduced to HRGN through participation in genetics telehealth training, where they also learned about the Partnership Trio Model. At Site A, there were one geneticist and one genetic counselor providing general genetics services across their healthcare system. When HRGN presented on the Partnership Trio Model, they saw this as a way to expand access to genetic services across their system.

Initially, the plan was that Site A would recruit PCPs across their system and states. Information was distributed with follow-up calls to introduce them to the project. The second strategy for Site A was to bring the model “in house.” The genetic counselor reached out to specialty nurses working in clinics that commonly referred to the genetics clinic. Out of this recruitment, one PCP who works at an urban, underinsured clinic demonstrated interest. This is a clinic that primarily serves the Hispanic community and has

SITE A: TRIOS MODEL



bilingual providers, as well as interpreters available as part of the delivery model. The PCP participated in training and began to implement the model based on the referral indications and testing algorithm that was provided. This project benefited the education of future physicians as family practice residents rotated through this clinic, which has provided them with exposure to the model and to genetics services. This clinic has been successful in completing first tier genetic testing. Since this is a non-profit clinic, Site A staff agreed to complete the genetic testing pre-authorizations for the PCP. A weekly connection between the PCP and the genetics team was an important strategy to coordinate activities and provide support. The genetics team felt targeting clinics that served minority populations may work well for the adoption of this model. The non-profit status of this clinic team was important to their adoption of this service.

As the genetic counselor commented, “We have large successes in that clinic. They (clinic staff) have a passion and a real connection with the families.” Parents were getting the first-tier assessments done with their PCP; as a result, families did not have to go to the lab, and it saved them one extra visit with the genetics team.

**Specialty clinic implementation.** At Site A, the Practice Trio Model was also modified to partner with pediatric specialty clinics and an adult oncology practice through connections with the nurse practitioners. These nurse practitioners (NPs) already had a good working relationship with the genetics team and frequently were calling about patients. Based on a combination of reasons for referral from these clinics, common questions from the NPs to genetics, and indications for which tier one testing could be helpful, the genetic counselor developed algorithms for each specialty clinic. The ongoing communication between the two groups has resulted in both an increase in referrals as well as more appropriate referrals to the genetic team. However, adoption of first tier assessments by these specialty teams did not occur as initially planned with the exception of one clinic.

As a result of building a strong partnership through the model, the genetic counselor was asked to participate in the Autism clinic. This clinic team was not able to bill without a genetic counselor as part of their team. Once the genetic counselor joined the team, the neurologist who was head of the clinic was then able to complete tier one assessments. The genetics counselor would follow-up with any abnormal results. Referrals were made, as necessary, to the medical geneticist. This was the most successful partnership between genetics and specialty clinics.

## LESSONS LEARNED

**Identification of a champion is key.** The success at Site A could be in part be attributed to finding a champion who embraced the concept and persisted in its implementation despite encountering barriers. Other states where a champion did not emerge faltered after the initial trainings and dialogues.

**Adoption of an innovation takes time.** Introduction into and uptake of a new and innovative practice in a clinic takes more time than was first anticipated. Two key elements emerged that affected time in implementation of the innovation, establishing relationships and the complexity of the system. For this model, there were multiple levels of relationships that were happening in parallel as the process was introduced and implemented. All were important to the success of the project and took time to develop. The key relationships were: a) between the HRGN project staff and the initial change agents; b) the PCP and their staff; c) the PCP and the partnering genetics team staff; and d) the administrative staff from each organization. The complexity of each of the organizations could also be a contributing factor.

**Cross-system work creates unique barriers.** In the second site (Site B), the efforts to work across health care systems within one state created insurmountable barriers, despite strong interest of PCPs and the genetics team to partner. In this case, they were working with three billing systems to try to determine the logistics of providing the services. As a result, the Partnership Trio model was not implemented at Site B. The champion of the model at this site recommended future implementation sites should be chosen who could implement the model within networks instead of across networks.



**Preauthorizations are time prohibitive.** It is time consuming to train PCP staff to conduct the genetic testing preauthorizations, especially if the testing volume is low at a specific practice. In addition, the internal processes and contracts vary at each site, which creates an additional difficulty in training multiple partners within different healthcare systems. In most situations, there is a need to identify other ways to support the genetic testing preauthorization process.



## IMPLEMENTATION SUMMARY

### Facilitated Connections

Two provider groups, home visitor programs and family networks and an autism clinic, were targeted for this project in order to support connections between patients and their families and genetic services. The home visitation work emerged from the Hispanic Access Advisory Committee’s (HAAC) recommendations that were part of the previous HRSA grant for the Regional Genetics Networks (2012 – 2017). In Year 3, a new project emerged that provided genetic counseling support in an autism clinic.

#### PARTNERING HOME VISIT PROGRAMS

- **First Steps Program (Missouri)**
- **Sooner Start (Oklahoma)**

#### PARTNERING FAMILY NETWORK PROGRAMS

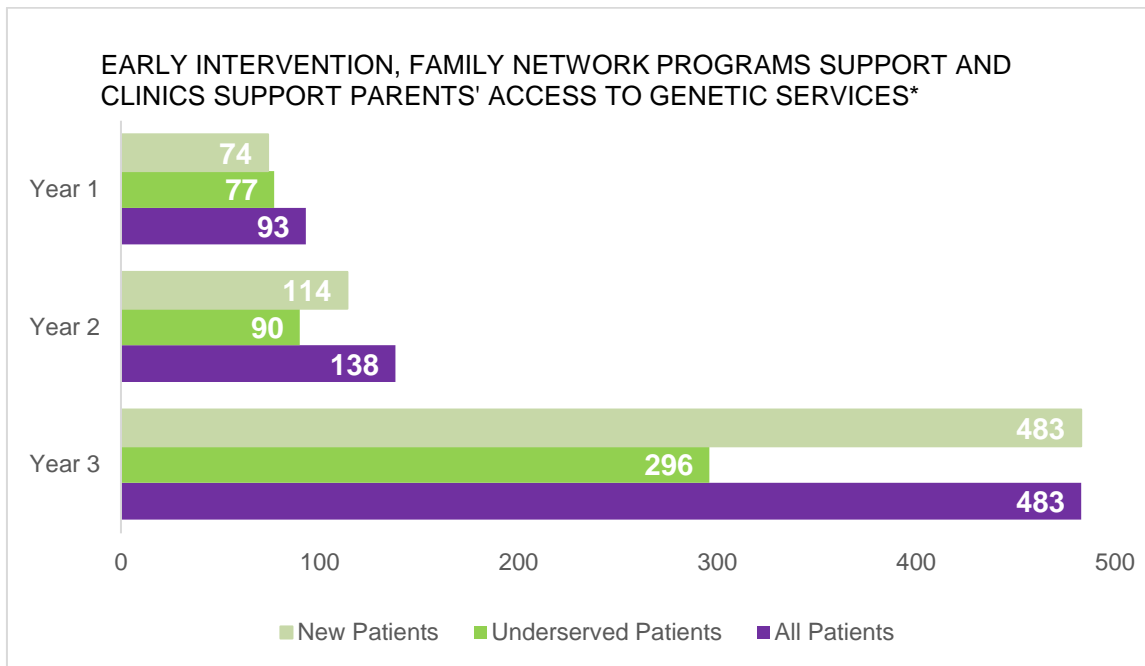
- **Family Together, Inc. (KS)**
- **Oklahoma Family Network (Oklahoma)**
- **Missouri Family Partnership (Missouri)**
- **Missouri Family to Family (MO)**
- **Family Voices (National)**
- **Family Voices of North Dakota (North Dakota)**

Materials and training were developed to help explain genetics services and address common questions and misconceptions about genetic services. An initial training was completed at the annual meeting in January 2018. Many family network and home visitation program staff (43) attended the training. These programs represented all eight HRGN states. HRGN has continued to have ongoing dialogues, formal or informal, with both family support networks and home visitation providers throughout the region. The six programs listed in the table formally partnered with HGRN to connect with families regarding access to genetics and submitted data regarding their efforts. A webinar was conducted with home visitation and family network partners on the data collection process for the performance measures. Programs from four states (i.e., Oklahoma, Kansas, Missouri, and Arkansas) committed to supported facilitated connections and data collection. In Year 2, trainings were conducted in Missouri and Oklahoma for early interventionists. Sustainability of efforts across these organizations over the three-year grant project was variable. Although the Early Intervention networks appreciated the information, they did not continue to participate in the data collection process after Year 1. The majority of the family support networks continued to partner with HGRN and provide data throughout the three-year grant period.

## Evaluation Summary

Facilitated contacts were documented by partnering programs, e.g., family network and early intervention programs, across the three grant years. The results found that there was a significant increase in facilitated connections by Year 3. Most of the facilitated connections included providing information on genetic conditions and about genetics resources in a state. Some providers also supported referrals for genetic services by initiating a conversation with the parents about genetics and/or assisting with the referral.

A primary emphasis of this grant award was to focus not only on newly identified patients, but to support those patients and their families from underserved areas. For purposes of HRSA, underserved was defined by nationally designated zip codes. **Across all three years, 71% of the families who received a facilitated connection to genetics lived in designated underserved areas.**



\*Includes patients seen in the Trio Model

Interviews were completed with key informants from each of the targeted family engagement networks to determine the benefits of their groups' participation in the grant activities and any challenges that were encountered. One family leader described inclusion of family support networks as part of the HRGN activities, "This is the best thing the Heartland has done."

## Benefits

**Increased connections between genetic providers and family support.** Family support providers indicated that participation in training gave them the tools and the encouragement needed to reach out to geneticists and other health care providers to identify how they could best work

together. These conversations resulted in new connections for the family support staff, as the health providers increased their awareness of the value of family-to-family support and who was providing it in their community. As one family leader commented, “Starting out, we developed a nice relationship with Dr. M. He did not understand the full role that we (family support) could play. He sent referrals on a rare occasion. Now there are many referrals.” An unanticipated by-product of these in-services with the genetics’ clinics and family support staff was increased referrals from the hospital, both in the oncology and NICU units.

**Participation in project training increased family support staff understanding of the Marshallese community.** One of the goals of this project was to improve the genetic providers’ understanding of the Marshallese community and to increase community members’ access to services. As one family support leader commented, “For me to hear L (Marshallese presenter) speak, gave me perspective of the Marshall Islands. That has been really helpful to our staff.” Due to this new awareness, one family support network reached out to a community coalition where there was a large Marshallese community in Oklahoma to see how they could be of support. They anticipated that to make those connections and determine mutual roles would take time, as this was a new relationship.

**Parents expanded their knowledge of genetics.** Family support network leaders reported that HRGN connections with family support programs resulted in families gaining more understanding of genetics through network staff facilitating conversations, and increased access to materials on genetic conditions. A number of strategies were used across networks including: conferences, one-on-one sessions with parents and distribution of materials. One network strategically reached out to younger families and advocates that had not previously been involved in their activities. They also intentionally placed families with children with genetic disorders on their advisory committee to increase their voice in the network.

## LESSONS LEARNED

**Family organizations may be best-suited to take the lead.** Initially, HRGN supported professionals to connect with the Native American and Marshallese communities in Oklahoma to determine the best strategy to support families from these communities access to genetic services. These contacts were not successful in generating a definitive plan. Family network staff expressed that they would be well-suited to take the lead in connecting to parents in underserved populations.

### Community Engagement to Expand Access to Genetic Services

One of the goals of HRGN was to engage medically underserved communities in order to expand their access to genetic services. This was accomplished through strengthening relationships with Marshallese, Spanish-speaking/Hispanic/LatinX, and Native American/American Indian tribal communities. Activities included the provision of resources, technical assistance, and training. From the partnerships with leaders in these communities, action steps were jointly planned and implemented at varying degrees across the communities.

**Marshallese community.** HRGN has partnered with a liaison from the Center for Pacific Islander Health in Arkansas who serves the Marshallese population. The first priority was to translate materials that could be used with families including:

- Arkansas newborn screening (NBS) parent information brochure
- Generic NBS parent information brochure for any state to use
- Developed “What is Genetics Services?” brochure
- Developed a generic Early Hearing Detection and Intervention information brochure
- Completed Newborn Screening video with Marshallese actors
- Supported two studies: 1) how best to obtain a medically relevant, but culturally respectful family history from a Marshallese patient, and 2) a pilot study to follow-up on a pattern of transient abnormal screen positives
- Developed an adult and pediatric genetics clinics devoted to Marshallese genetics patients with trained medical interpreters and community health workers. However, this was postponed due to COVID-19. The planned implementation will take place in 2021 if COVID-19 restrictions are lifted or telehealth can be implemented for this community
- Convened a national training for Marshallese interpreters in medical genetics. This training brought together nearly 40 Marshallese interpreters from 12 states for a 2-day. Cindy Roat, author of “Bridging the Gap,” was the trainer. The training opened and closed with traditional Marshallese ceremonies. Many lessons were learned including: Marshallese interpreters have varied experience and training; community health workers may be a better fit within this community than someone who acts solely as an interpreter; a medical genetics glossary is needed before a full interpreter training can be provided. As such, HRGN developed a protocol to implement the development of the glossary. Unfortunately, the COVID pandemic greatly affected the Marshallese community resulting in a halt to the glossary’s progress.

A major accomplishment was the development of clinical guidelines that was based on both appropriate clinical and cultural practices. The Marshallese community leader indicated that this was an extremely important resource to genetic counselors. As she reported, “The consulate general (Marshallese) was involved in the activity. He is very anxious to get the tips sheet out. This will be a tangible product that can be disseminated.”





**Spanish-speaking Hispanic community.** We continue to carry out the recommendations of the Hispanic Access Advisory Committee that began from a project from the previous grant cycle (2012 – 2017), including training of home visiting professionals and developing materials that explain genetic services and address common questions about genetic services. Three videos were developed that support families' access to genetic services. The topics covered were: a) newborn screening; b) information on genetic services; and c) use of interpreters. Links to the videos:



- <https://www.youtube.com/channel/UC1qysK3DUhkP8iJIQrVdRuA>
- <https://www.heartlandcollaborative.org/for-families/resources/>

**Native American/American Indian community in Oklahoma.** Oklahoma Family Network, a contracted partner with HRGN, conducted a training for parents who are Native American/American Indian and were providing support to parents in tribal areas. In addition, two presentations were made (see page 15) to tribal organizations, which have opened doors to ongoing conversations for future collaborations.

## Genetic Consultation to Increase Access to Genetics Services

### IMPLEMENTATION SUMMARY

During the third year of the grant, Oklahoma found itself without any geneticists in their state. Genetic providers reached out to HRGN staff to help identify solutions. HRGN staff facilitated a connection with Dr. Brad Schaefer, a geneticist at the University of Arkansas for Medical Sciences, Northwest. Dr. Schaefer, who is a leader in telehealth, a member of the HGRN staff, and also licensed in Oklahoma, was able to provide critical clinical consultation to neonatologists, genetic counselors and other providers in Oklahoma to support the newborn screening evaluation and management for newborns with abnormal screening results until they were able to hire and credential new geneticists.

## Quality Improvement Activities

### IMPLEMENTATION SUMMARY

Building on previous work on quality metrics development, the Genetic System Assessment (GSA) tool, HRGN completed the development of the GSA tool version 3.0. Based on previous implementation efforts, some elements were removed and replaced with other elements based on

another round of literature review. HRGN has sought advice from the Steering Committee in its April annual meeting (2019) to finalize the tool and discuss potentially another round of implementation with the revised instrument. A manuscript on the development and pilot implementation of GSA v.2.0 was published in Genetics in Medicine (Chou et al., 2019).

HRGN identified a Quality Improvement (QI) project based on a barrier that was identified in the practice model--laboratory preauthorization. Plans were made to convene a task force, develop a protocol, and implement the protocol using standard QI methodologies for evaluation and modification.

## Innovative Telehealth Delivery Models

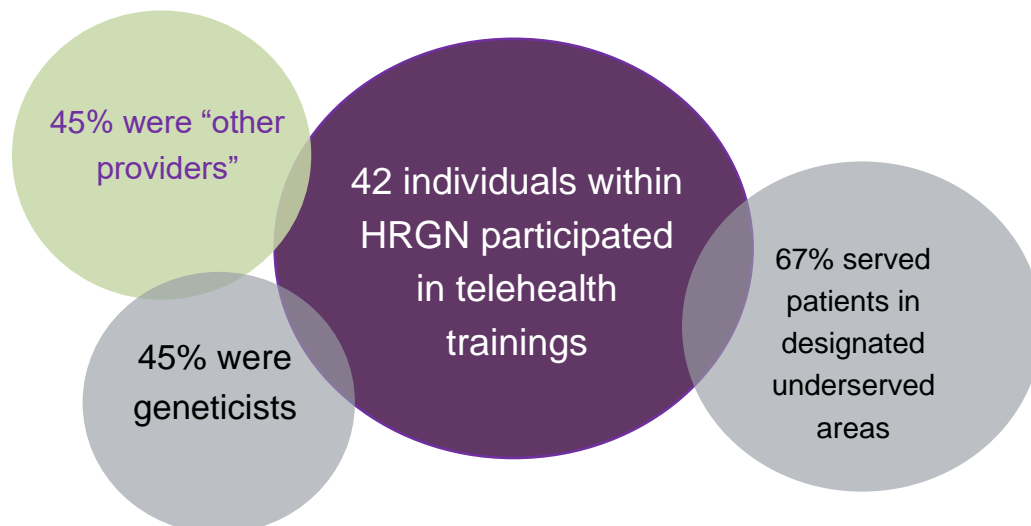
### IMPLEMENTATION SUMMARY

#### Training and Technical Assistance

HRGN continues to be a leader in telehealth training and technical assistance. HRGN provided telehealth consultation and/or trainings to the Midwest, Mountain States, NERGN, and NYMAC RGNs to support them in promoting telehealth in their respective region. The following trainings were completed:

- A tele-genetics training for genetic counselors was implemented in Iowa in 2017.
- A training was offered for participants across five states. Participants represented diverse backgrounds including those from public health, primary care, medical genetics, and physician assistants in 2018.
- HRGN provided multiple tele-genetics trainings for Midwest RGN and Mountain states in 2019.
- Tele-genetics training for medical geneticists and residents was held in 2020.

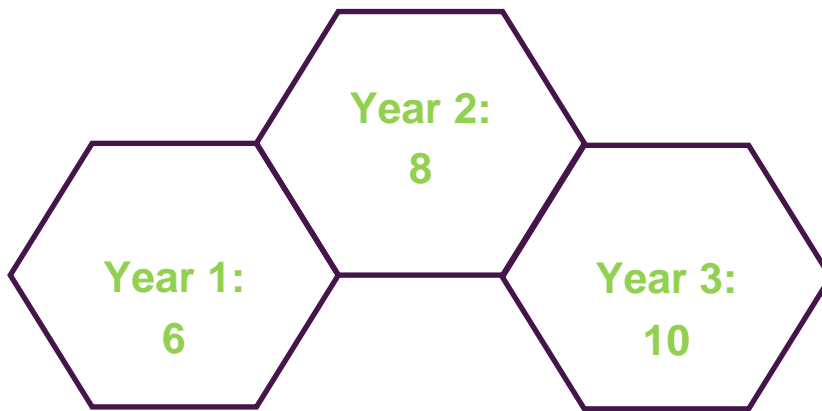
Most of the providers who participated in these trainings practiced in states outside of the HRGN.



## TELEHEALTH CLINICS

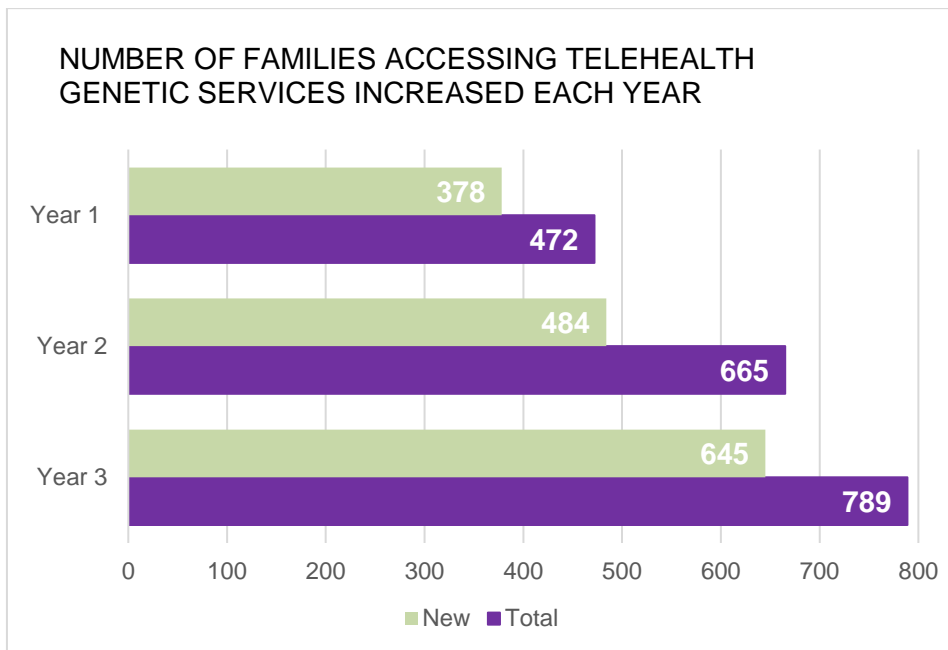
At the start of this three-year project period, there were six originating clinic sites and one distance site that were sponsored by the project. These were located in both Arkansas and Kansas. By the end of the project, ten originating clinic sites were supported by grant funds. These sites were expanded to not only include Arkansas and Kansas, but also Oklahoma. This was a 67% increase from the baseline data.

### HRGN SUPPORTS TELEHEALTH CLINICS ACROSS THE REGION



Telehealth sites increased since Year 1 by 67% which resulted in an increase of patients seen across the three years.

Dr. Brad Schaefer was the genetics provider delivering services across the ten sites. Across the three years, there was an increase in the number of patients that were seen through telehealth. The number of new patients (a new requirement for HRSA reporting starting Year 2) was based on an estimated percentage (80% of the total) because systems were not in place to track new patients. The majority (84%) of the patients seen in telehealth services were from underserved areas.



84% of the patients seen in telehealth services were from underserved areas

## Resources to Genetic Service Providers, Public Health Providers, and Families

### IMPLEMENTATION SUMMARY

#### Extension for Community Healthcare Outcomes (ECHO)

HRGN collaborated with Show-Me ECHO in Missouri to provide a series of ECHO sessions in the region that include case discussions and didactic presentations. The purpose of the series was to increase participants' understanding of genetics evaluations, genetic counseling, family support, and newborn screening as a system. The series was completed in Year 2 with Continuing Medical Education credits provided. There were 107 providers that attended the ECHO series. Topic areas presented were:

- “Genetics evaluation for the child with developmental delays and/or autistic behaviors: The primary care provider’s role”
- “Newborn and infant hearing screening: When to act”

#### Partnerships with Parent Organizations

A key activity of HRGN is to collaborate with parent organizations in each state to expand its reach to families. Four strong partnerships emerged with Oklahoma Family Network, Kansas Families Together, North Dakota’s Family Voices, and Missouri’s Family Partnership for Children and Youth with Special Health Care Needs (SHCN). Activities have included bidirectional training and resource sharing with the goal to support patients and families seen in the Heartland genetic clinics.



New educational resources were developed based on the needs of staff to support their discussions with families regarding genetic services. Specific activities included:

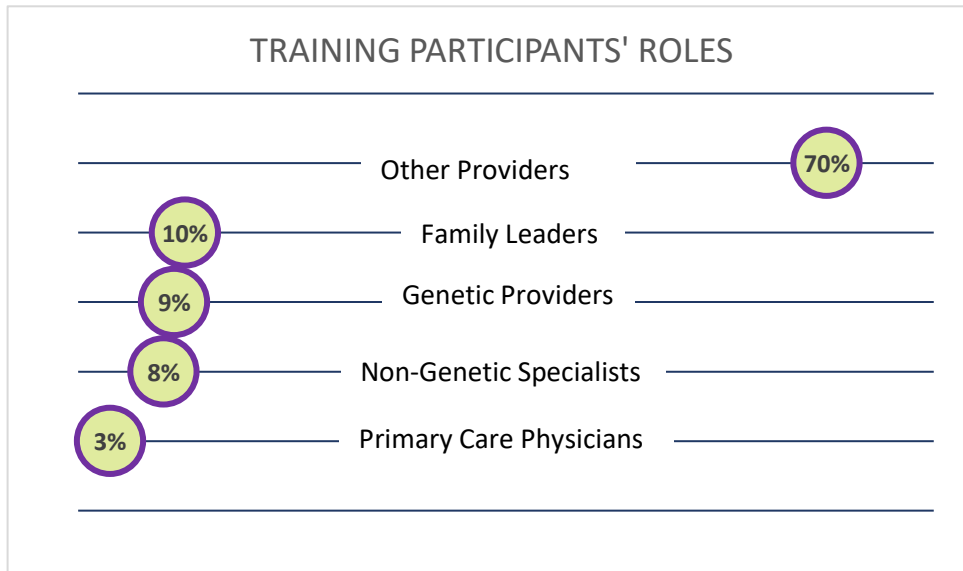
- Facilitated training for early interventionist and the family network in Missouri in 2019;
- Hosted an Advocate Leadership Retreat in Dallas, Texas in 2019;
- Facilitated training for early interventionist in Oklahoma in 2019;
- HRGN family network training in 2019.

HRGN collaborated with Baby's First Test / Genetic Alliance, and Family Voices to develop a video series on newborn screening, genetic services, and using an interpreter.

## Training

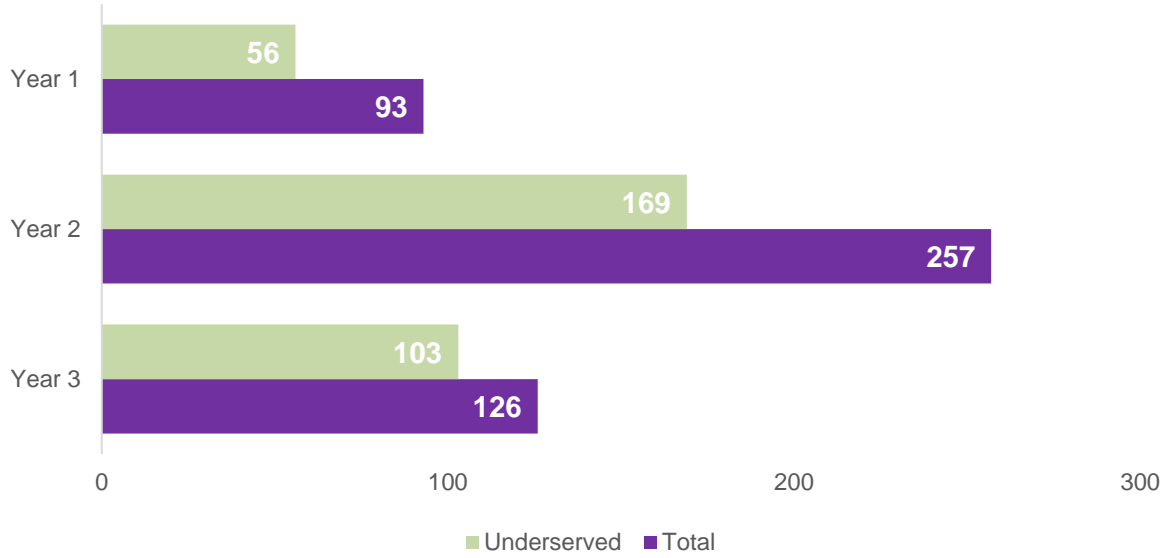
A broad range of topics were identified for training across the project's three years. Topical areas included:

- Trio Partnership Model
- Telehealth practices
- Interpreter Training on Genetics content



A number of in-person trainings were scheduled for the spring of 2020. These were cancelled due to the COVID-19 pandemic. As a result of the pandemic, there were few individuals participating in training compared to previous years. Overall, 476 participants received trainings that were offered across the three years. A total of 69% of the participants lived in underserved communities.

PARENTS AND PROVIDERS PARTICIPATED IN TRAININGS THAT COVERED A BROAD RANGE OF GENETIC RELATED TOPICS



## Dissemination Activities

### Publications

Chou, AF, Mulvihill, JJ, Kaye, C., Mann, S., Williamson, L. (2019). Developing a genetic services assessment tool to inform quality improvement efforts in state genetic service delivery. *Genetic Medicine*, Apr: 21 (4): 955-964. Doi: 10.1038/s41436-018-018-0141-2.

Hallford, H.G., Coffman, M.A., Obregon-Tito, A.J., Herrera Morales, A., and Williamson Dean, L. Access Barriers to Genetic Services for Spanish Speaking Families in States with Rapidly Growing Migrant Populations. (2020) *Journal of Genetic Counseling Special Issue: Minority and Health Disparities in Research and Practice in Genetic Counseling and Genomic Medicine – Part 2, 29(3)*, pp. 365-380. doi: 10.1002/igc4.1195. Epub 2019 December 12.

Blocker, K., Hallford, H.G., McElfish, P., Danylchuk, N.R., and Williamson Dean, L. Eliciting culturally and medically informative family health histories from Marshallese patients living in the United States. (2020) *Journal of Genetic Counseling Special Issue: Minority and Health Disparities in Research and Practice in Genetic Counseling and Genomic Medicine – Part 2, 29(3)*, pp. 440 – 450. doi: 10.1002/igc4.1249. Epub 2020 April 28.

### Presentations

Chou, A. & Dean, L. (2018). Trios Partnership Model. Presentation at the Oklahoma Family Practice conference.

Chou, A., Chen, X., & Dean, L. (2019). Genetic System Assessment: A Survey of Quality Measurement for State Genetic Services. American Public Health Association Annual Conference, Philadelphia, PA. November.

Chou, A., Duncan, A., & Dean, L. (2019). Integration of Primary Care and Medical Genetics for Medically Underserved Populations: Developing and Implementing Strategies. American Public Health Association Annual Conference, Philadelphia, PA. November.

Chou, A., Duncan, A., Coffman, M., Lena, A., & Williamson Dean, L. 2019. "Integration of Primary Care and Medical Genetics Serving American Indian Populations: A Scoping Review of Barriers and Strategies." Tribal Public Health Conference, Tulsa, OK. April.

Chou, A., Lena, A., Dean, L. 2019. Strategies to Integrate Primary Care and Medical Genetics Services to Improve Access to Care in the American Indian Populations. Inter-Tribal Emergency Management Coalition Summit, Shawnee, OK June.

### Video Productions

A major project over the grant period was the development of educational videos. The purpose of these videos was to increase the understanding of genetics for two underserved populations, the Marshallese and Hispanic. These videos were created in collaboration with members of these communities. They would be deployed to coincide with the Newborn Screening Month.

All are available on the Heartland Regional Genetics Network's YouTube channel:

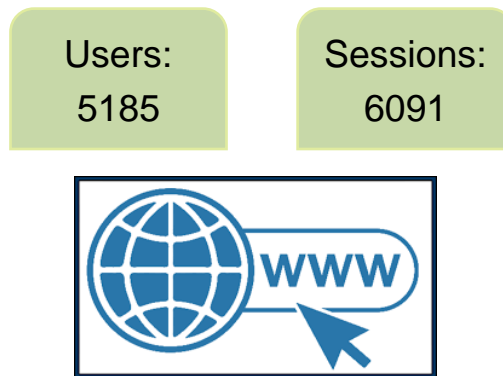
<https://www.youtube.com/channel/UC1qysK3DUhkP8iJIQrVdRuA>

- Spanish: (1) Newborn Screening; (2) Genetics Services; and (3) Using an Interpreter
- Marshallese: Newborn Screening

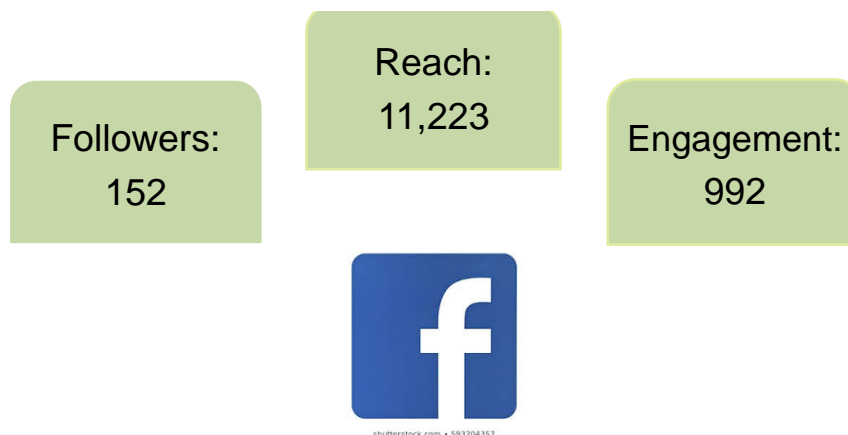
## Social Media

Facebook is the only social media outlet for the HRGN. Additionally, HRGN has a website and a YouTube channel. Together, these media are used to disseminate information regarding their activities. By the end of the third year, HRGN had high travel at both the website and Facebook.

### Website Connections in 2019-2020



### Facebook Connections in 2019-2020





## National Performance Measures: HRGN Results

Heartland collected data as part of the National Performance Measures. As part of that evaluation process, each of the key strategies was cross-referenced with the elements of the National Performance Measures. These are summarized in the charts below.

Partnership Trios Model	Performance Measure	#
	# that receive education or training on genetics	1a
	# of patients for whom RGN facilitated connections to geneticists	2
	# trained on telehealth modalities for genetics	3
	# of sites that use telehealth modalities	4
	# of patients for whom telehealth modalities were used	5

Home Visitor and Family Network Partnership	Performance Measure	#
	# that receive education or training on genetics	1a
# of patients for whom RGN facilitated connections to geneticists	2	

New Clinic Services	Performance Measure	#
	# of patients for whom RGN facilitated connections to geneticists	2
	# trained on telehealth modalities for genetics	3
	# of sites that use telehealth modalities	4
# of patients for whom telehealth modalities were used	5	

Telehealth Training and TA	Performance Measure	#
	# trained on telehealth modalities for genetics	3
	# of sites that use telehealth modalities	4
# of patients for whom telehealth modalities were used	5	

The results of the HRGN National Performance Measures are summarized in the following table. Data represents Year 1 through Year 3.

### Summary of HRGN Performance Measure Results

National Performance Measures		2017-2018	2018-2019	2019-2020
Training and Resource Support	1a. Number of providers, individuals, and families that received education or training on genetics from the RGN program.	93	257	126
	1b. Number of RGN resources used/accessed by providers, individuals, and families.	1	3	4
	Website Users	2314	4197	5185
	Website Sessions	2714	5555	6091
	Facebook Followers	207	234	152
	Facebook Reach	207	9240	11223
	Facebook Engagement	210	982	992
	3. Number of providers trained through an RGN-supported event in either teleconsultation or telemedicine.	34	6	2
Clinic Visits and Facilitated Connections	2. Number of patients for whom the RGN program facilitated connections to a geneticist.	74	58	483
Telehealth Consultation or Clinic Visits	4. Number of RGN sites that used/provided teleconsultation or provided telemedicine for at least one genetics patient in the past year.	6	8	11
	5. Number of patients who were seen by an RGN-supported provider using telemedicine and the number of patients for whom a RGN geneticist provided teleconsultation.	378	484	645



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The University of Nebraska Medical Center's  
Munroe-Meyer Institute: A University Center of Excellence  
of Developmental Disabilities

