

Heartland Regional Genetics Network— Projects and Products

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Aims

- ▶ Aim 1: Support the HRGN infrastructure to continue current work in improving access to genetic services
- ▶ Aim 2: Engage underserved communities to develop strategies in improving accessibility to genetic services based on needs and preferences specific to each community
- ▶ Aim 3: Implement innovative telehealth clinical genetics service delivery models and provide technical assistance, education, and training in telehealth
- ▶ Aim 4: Create dynamic learning communities to facilitate information exchange and knowledge sharing among genetic and non-genetic providers
- ▶ Aim 5: Improve the quality of care in genetics and access to genetic services for patients and their families

Aim 2: Engage underserved communities to develop strategies in improving accessibility to genetic services based on needs and preferences specific to each community

Spanish-speaking and Marshallese communities (Year 3)

AWARENESS

- Interviews - mothers of CYSHCN
- Educational events (NBS, advocacy, health screenings)
- EHDI video
- Part 2 - video evaluation project
- Part 2 - use of a Chatbot for improving access
- Started US health care system video series

ACCESS

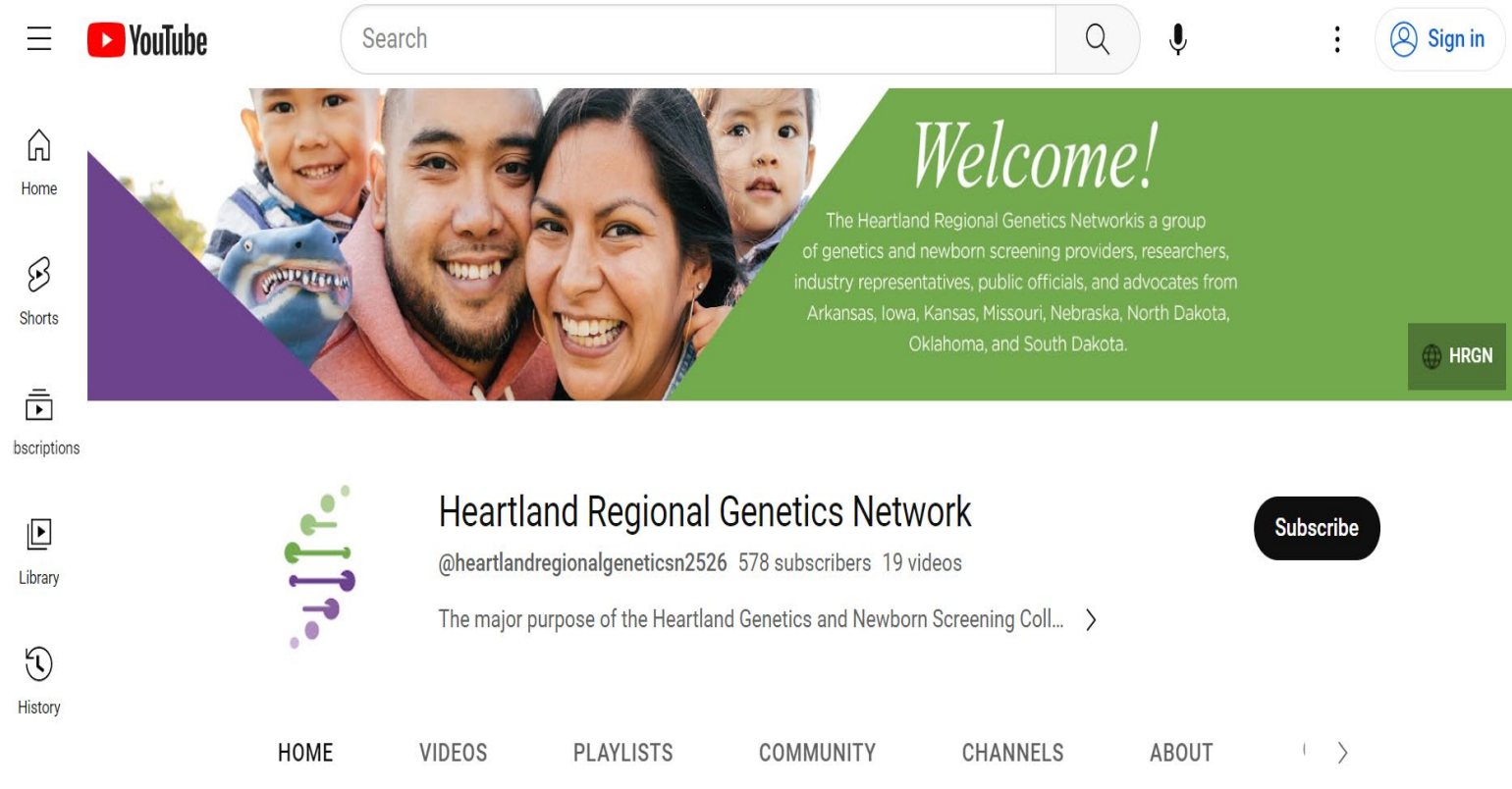
- Referral to genetics
- Interviews
- EHDI parent letters from AR DOH

QUALITY

- Translated information about Down syndrome
- Interviews
- Medical genetics glossary
- Tips for American providers
- Dr. Hays' project
- Advocate Leadership Training
- Planning- piloting videos in clinics

Products: Videos (Spanish and Marshallese)

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



The screenshot shows the YouTube channel page for the Heartland Regional Genetics Network. The top navigation bar includes the YouTube logo, a search bar, a microphone icon, a menu icon, and a 'Sign in' button. The left sidebar contains icons for Home, Shorts, Subscriptions, Library, and History. The main content area features a large banner image of a smiling family (a man, a woman, and two children) with a green overlay on the right. The overlay contains the text 'Welcome!' and a description of the network. Below the banner is the channel's name, 'Heartland Regional Genetics Network', its handle '@heartlandregionalgeneticsn2526', subscriber count '578 subscribers', and video count '19 videos'. A 'Subscribe' button is located to the right of the channel information. Below the channel name is a short description: 'The major purpose of the Heartland Genetics and Newborn Screening Coll...'. At the bottom, there is a navigation bar with links for HOME, VIDEOS, PLAYLISTS, COMMUNITY, CHANNELS, and ABOUT.

YouTube

Search

Sign in

Home

Shorts

Subscriptions

Library

History

Welcome!

The Heartland Regional Genetics Network is a group of genetics and newborn screening providers, researchers, industry representatives, public officials, and advocates from Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota.

HRGN

Heartland Regional Genetics Network

@heartlandregionalgeneticsn2526 578 subscribers 19 videos

Subscribe

The major purpose of the Heartland Genetics and Newborn Screening Coll... >

HOME VIDEOS PLAYLISTS COMMUNITY CHANNELS ABOUT

Marshallese written materials

Quick Tips for Providers Serving Marshallese Patients & Clients

What should healthcare providers do or understand?	Why is this helpful or important?
<ul style="list-style-type: none"> Say "lakwe" (pronounced YOK-way) at the start of the appointment. 	<ul style="list-style-type: none"> This shows that the provider cares enough to learn something about the patient's language and culture.
<ul style="list-style-type: none"> Introduce yourself, "lakwe, et a in (pronounced een) (insert your name)." Et a in? (this means, "What is your name?") Then, thank the patient for coming to the appointment. 	<ul style="list-style-type: none"> This helps build the patient-provider relationship.
<ul style="list-style-type: none"> Marshallese families are very large and include extended family as well as non-biological family members. 	<ul style="list-style-type: none"> Providers should be aware for this in order to ask the appropriate questions when taking a family health history.
<ul style="list-style-type: none"> Explain why each family and personal health history question 	<ul style="list-style-type: none"> Patients will be more willing to give accurate

Etke eaurok Newborn Screening?

- Mōkaj ñan kakōlkōl im kōmadmōd ej kejpārok mour.
- Ewor kōmadmōd ñan aolep kakōlkōl ñan niñniñ ko rej kab lotak.
- Jet niñniñ rej lotak tok im ejmour lōmaer, bōtaab ewor juōn nañnimij elap im ettino ippāer.
- Kakōlkōl ej kamōkaj kiten kōmadmōde niñniñ ko, elōñ kōttan mokta jen aer enjake jabdeiwt kakōllan nañnimij ko.
- Emāroñ wor nañnimij ko rellap ippān niñniñ ko meñe emman an baamle ko mour im rejañin kar nañnimij.

Ialmen Newborn Screening?

- 24-48 awa elkin an niñniñ eo lotak, nāāj bōk jejo bil in bōtōktōk jen jimin neen im likit ion juōn kain pepa, kōttar an mōra, innem jikinlōk ñan jikin bōk bōtōktōk eo.

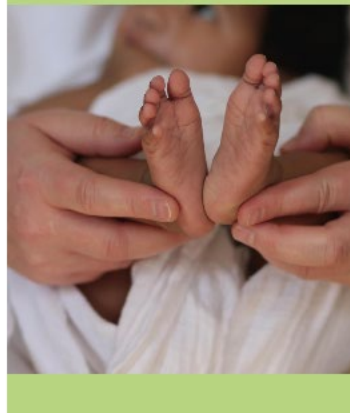
What can a healthcare provider say to a Marshallese patient to make the patient feel more comfortable?

- Say "lakwe" (pronounced YOK-way) at the start of the appointment.
 - "lakwe" is the Marshallese word for hello. Saying this simple phrase shows the patient that the provider cares enough about the patient to learn something about their language and culture.
- Introduce yourself, ask their name, and thank the patient for attending the appointment.
 - This helps to cultivate rapport. Talking about non-medical matters shows that the provider cares about the patient on a more personal level.

What services can a healthcare facility, hospital, or clinic provide to encourage the Marshallese population to seek healthcare when ill?

- A Marshallese community health worker (CHW) should be present at the facility and available during the patient's entire visit.
 - A CHW can interpret both spoken language and non-verbal cues between the

Newborn Screening ilo Heartland



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University of Arkansas for Medical Sciences
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Email: hrc@UAMS.edu

For Family Support Contact:
Family Voices: familyvoices.org
Family to Family: family-to-family.org
Hands and Voices: handsandvoices.org
Parent2Parent: p2pusa.org

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Eaurōk bwe kwon
bōklōk ajiri eo nejum
im kakilen lojilñin elañe
kwoj loe ke erumij an
jelā kenaan

Kakōlle ko ñan Jarroñroñ

Ajiri eo nejum emaroñ jarroñroñ elañe ewōr wāwein kein ibben:

- Ñe ewor ami abnōō
– MŌKAJ KAKE!
- Elōñ jarroñroñ ilo baamle eo
- Elōñlōk jen 5 raan in an bed ilo Neonatal Intensive Care Unit eo (NICU)
- Ej chemotherapy
- Ekar wor kij ko renana ilo ien bōrqro ekoba CMV, bacterial im viral meningitis

1-2 ibwiljin 1000 niñniñ ko rej uñ aer allōñ im lotak, ej alikkar aer jarroñroñ

~1 ibwiljin 200 niñniñ ko ilo NICU ej jarroñroñ

Elak mōkaj ad jelā ke niñniñ eo nejum jarroñroñ, e mōkaj ad bukot kilen bwe en jelā kenaan.



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For Family Support Contact:
Family Voices: familyvoices.org
Family to Family: family-to-family.org
Hands and Voices: handsandvoices.org
Parent2Parent: p2pusa.org

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EHDI
KAKŌLKŌL IM
KŌMADMŌD
ÑAN BŌBRAE
IKIJJEN LOJILÑIN
NIÑNIÑ

Aim 4: Create dynamic learning communities to facilitate information exchange and knowledge sharing among genetic and non-genetic providers

Provider and family resources

► Project ECHO series

- <https://www.heartlandcollaborative.org/educational-resources/echo-series/>
- Next series coming in Fall 2023!!

Heartland Project ECHO Summer 2022 Series

Session: “The genetic testing journey: who, what, and how” -- *From patient to provider to payment, experts share tips and tricks to make the genetic testing process less painful.*

Provider and family resources

► Resource Center

► <https://www.heartlandcollaborative.org/resource-center/>

Heartland Collaborative Resource Center

Start by reviewing how to use our center and then create your account or login to start creating your favorites collection!

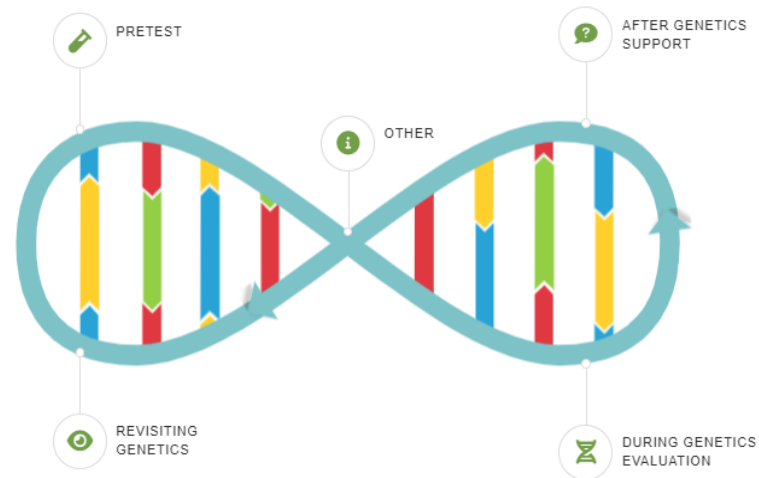


Search resources by keyword

SEARCH

Where Are You In The Process?

Click on the part of the process where you are to explore more resources.



Provider and family resources

► Resource Center

- <https://www.heartlandcollaborative.org/resource-center/>

I Am A...

PATIENT

PROVIDER

ADVOCATE

Provider and family resources

► Resource Center

► <https://www.heartlandcollaborative.org/resource-center/>

Welcome to the Resource Center

Here you will find a variety of resources that have been curated to provide up-to-date and accurate information on genetics. Our resource center was designed to make your search for information simple and informative, while offering quick and easy ways to share your results with others.

LOGIN

CREATE AN ACCOUNT

How does it work?

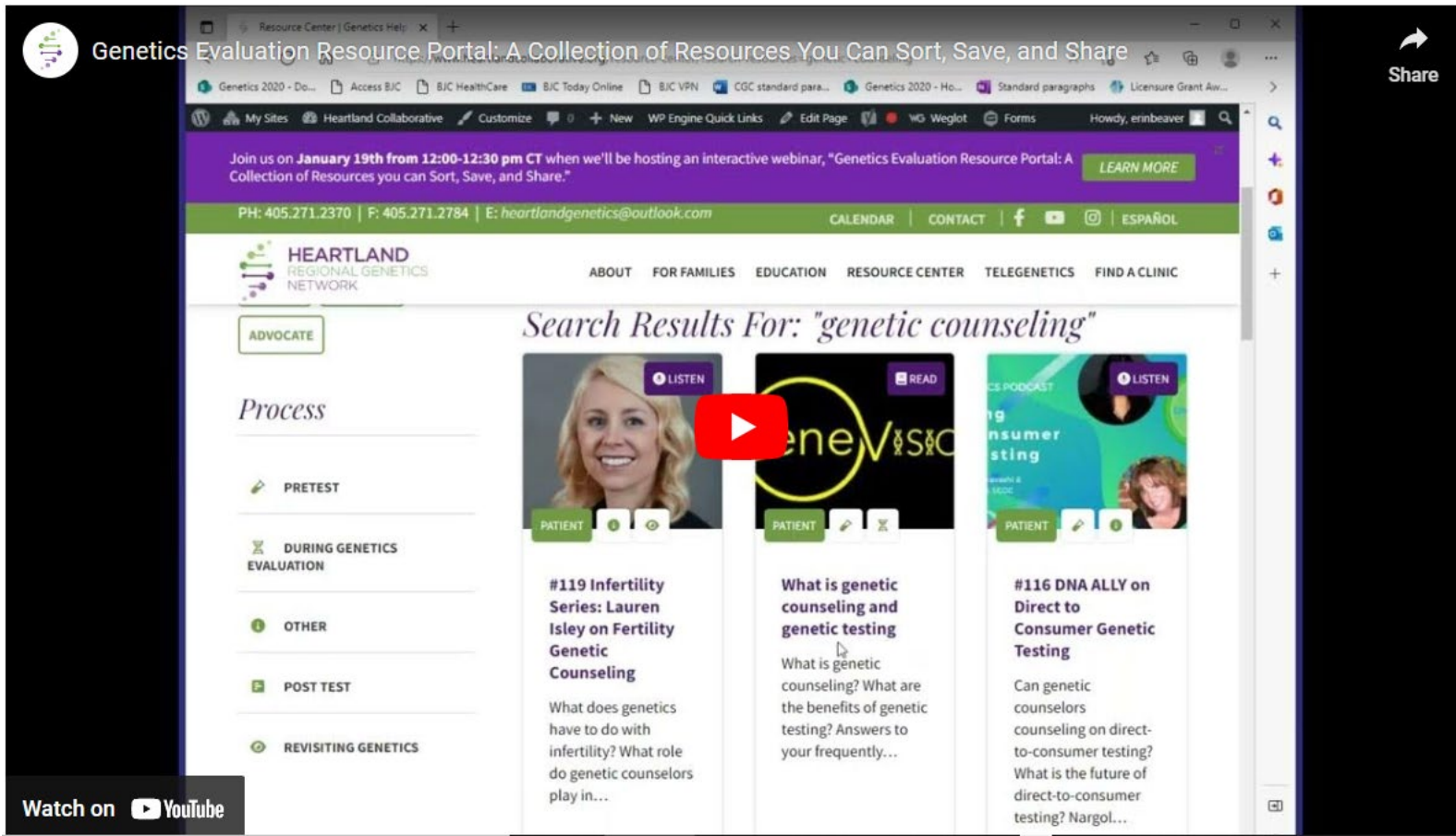
There are three main parts to our resource center: audience, category, and search. Additionally, we include references to the format of each resource to give you different ways to digest information.

Provider and family resources

► Resource Center

► <https://www.heartlandcollaborative.org/resource-center/>

Watch Tutorial



The screenshot displays the Heartland Collaborative Resource Center website. The header includes the site name, contact information (PH: 405.271.2370, F: 405.271.2784, E: heartlandgenetics@outlook.com), and navigation links (CALENDAR, CONTACT, ESPANOL). The main content area shows search results for "genetic counseling". On the left, a sidebar lists categories: ADVOCATE, Process, PRETEST, DURING GENETICS EVALUATION, OTHER, POST TEST, and REVISITING GENETICS. The search results include three items: a video titled "#119 Infertility Series: Lauren Isley on Fertility Genetic Counseling", an article titled "What is genetic counseling and genetic testing", and a podcast titled "#116 DNA ALLY on Direct to Consumer Genetic Testing". A red play button icon is overlaid on the first video result. The bottom of the page features a "Watch on YouTube" button.

Provider and family resources

► Map of Genetics Clinics

► <https://www.heartlandcollaborative.org/genetics-clinics/>

Find a Genetics Clinic Near You

We're proud to help families and advocates of patients locate nearby genetics clinics. We also Region to help diagnose and treat medical conditions.

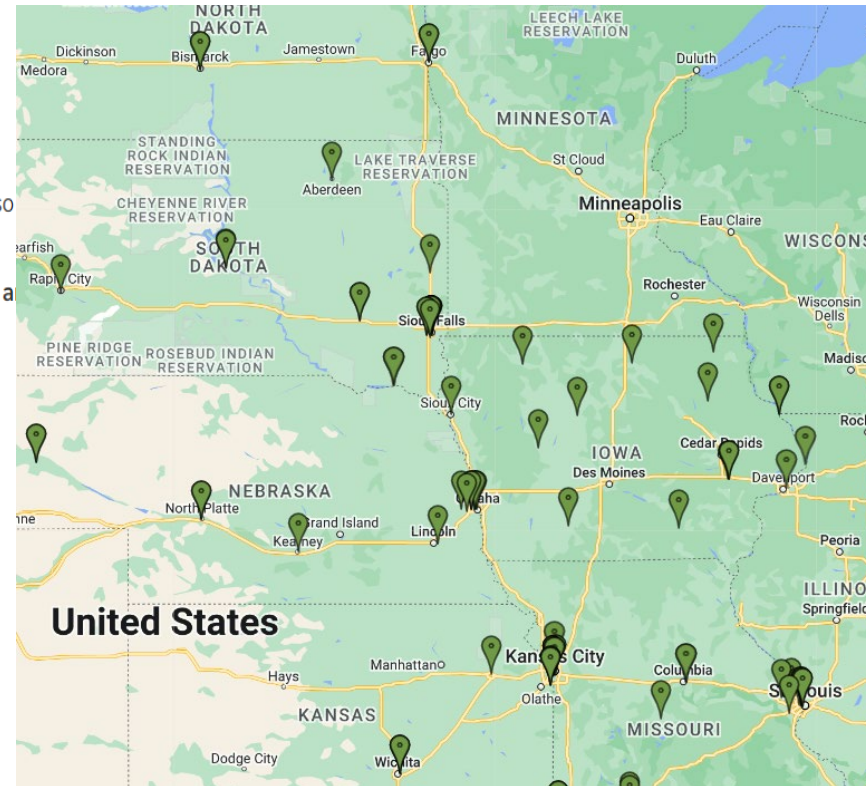
To search genetics clinics nationally in states outside of the Heartland Regional Genetics a

To submit a genetics clinic for approval to our national directory, please [click here](#).

Clinic Type ▼

State ▼

Go



Provider and family resources

► Individualized Health Plan (IHP)

HEALTHCARE PLAN	
School District Name	
Student: <input type="text"/>	
Date of Birth: <input type="text"/>	
Parent: <input type="text"/>	Physician: <input type="text"/>
Health Condition: <input type="text"/>	Nursing Diagnosis: <input type="text"/>
Outcome:	
<ul style="list-style-type: none">Staff will report understanding of care plan.Care plan will be carried out as written.<input type="text"/>	
Assessment/Symptoms (individualize to student):	
<ul style="list-style-type: none"><input type="text"/><input type="text"/><input type="text"/><input type="text"/>	
Plan (individualize to student and allow for maximum student independence):	
Individual Responsible	Interventions/Accommodations
<input type="text"/>	<input type="text"/>

Provider and family resources

Care Notebook
App: SUMMER 2023

The screenshot displays the 'Forms' section of the Care Notebook App. At the top, there is a navigation bar with a back arrow, the text 'Home', the title 'Forms', and a sort icon (up and down arrows). Below the navigation bar, there is a grid of 10 form tiles arranged in 5 rows and 2 columns. Each tile contains a title, a subtitle, an icon, and a small illustration of a person. The forms are:

- Allergy Log**: Subtitle 'Olivia Medication', icon of a person with a speech bubble.
- Appointment Log**: Icon of a person with a calendar.
- Blood Pressure Tracking Chart**: Icon of a person with a blood pressure cuff.
- Blood Sugar Tracker**: Icon of a person with a blood sugar meter.
- Daily Medication Tracking**: Icon of a person with a pill bottle.
- Dental Care Record**: Icon of a person with a dental chair.
- Diet Tracking Form**: Icon of a person with a plate of food.
- Growth Tracking Form**: Icon of a person with a growth chart.
- Hospital Stays Tracking**: Icon of a person with a hospital bed.
- Lab Work, Tests and Procedures**: Icon of a person with a test tube and a pencil icon.

Aim 5: Improve the quality of care in genetics and access to genetic services for patients and their families

Efforts to improve quality- Year 4

- ▶ Share what we learn from the Marshallese and Hispanic/Latino communities, and from our families with health care providers & families through **social media, continuing education, tools, and strategies**
 - ▶ Provider Tip Sheet (Marshallese)
 - ▶ Creating tools for providers
 - ▶ Consenting videos in Marshallese and Spanish
 - ▶ Spanish video sharing prior to clinic
 - ▶ Parent testimonial videos - Spanish
 - ▶ Advocacy Training amongst the Marshallese
 - ▶ Medical Genetics Glossary with interpreter trainings - Marshallese
 - ▶ Care Notebook App - English, Marshallese, Spanish
 - ▶ Individualized Health Plan - English, Marshallese, Spanish
 - ▶ Video tutorial series on the US Health Care System - Marshallese