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/UC1qysK3DUhkP8iJlQrVdRuA
Marshallese written materials

Quick Tips for Providers Serving Marshallese Patients & Clients

What should healthcare providers do or understand?

- Ask "Imalek?" (paralyzed) NOW in the start of the appointment.
- Introduce yourself, name, and in your mother tongue.
- Poj pasek? (Do you have a patient card?)
- Explain the purpose of the appointment.
- Make care facilities support very long and detailed-family history.
- Explain why family and personal history is important.
- Discuss with the patient the social, cultural, religious, and language differences of the appointment.

Why is this helpful or important?

- The care provider can provide appropriate information to the patient, the family, and the community.
- The documentation of patient's information is useful for future appointments.
- The patient's understanding of the appointment is important for a successful appointment.

What can a healthcare provider say in a Marshallese patient to make the patient understand? (Examples)

- "Tales" (Understanding Following), at the start of the appointment:
  "Askew iror? (What's wrong?)
  "Makke oloni? (Do you have any questions?
  "Tales, iror, ikiul ambir? (What's wrong with you?"

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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/](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/
Provider and family resources

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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.

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
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 area. To submit a genetics clinic for approval to our national directory, please click here.

Search by company name, city, or zip  Clinic Type  State  Go
Provider and family resources

Individualized Health Plan (IHP)
Provider and family resources

Care Notebook
App: SUMMER 2023
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
    - Consent 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