



National Coordinating Center
for the Regional Genetics Networks

Projects from Across the NCC/NGEFSC/RGN System

Alisha Keehn, MPA
NCC, serving as a RGN Project
Tour Guide

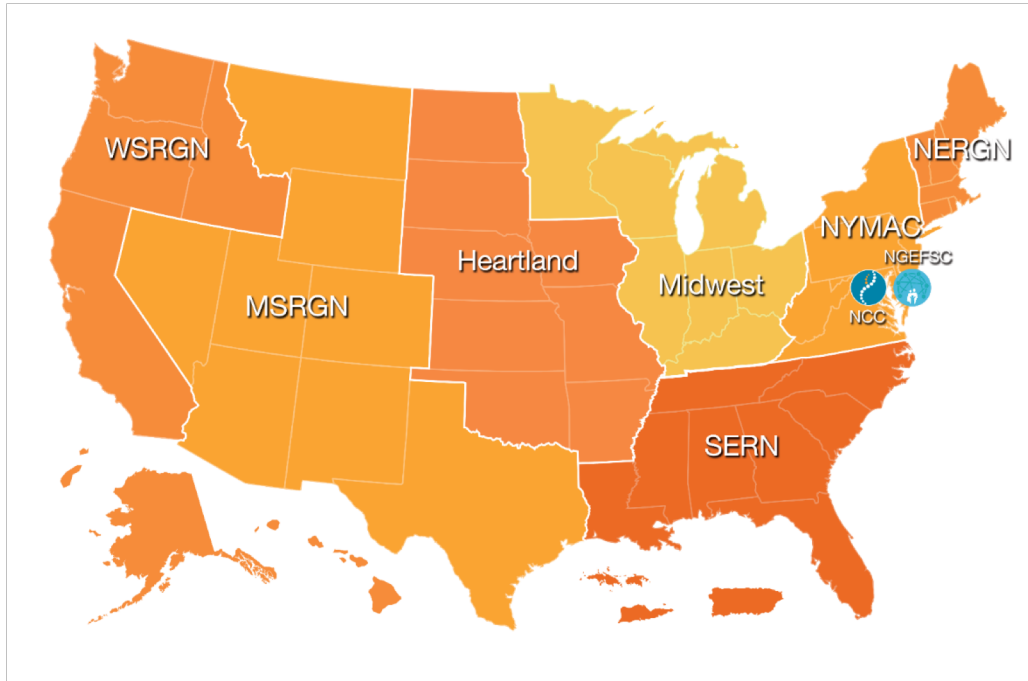
(Certification pending)

February 15, 2010

I am going to take you on a little RGN Project Highlights tour....

Disclaimer: as your tour guide I am here to give you an overview of the projects and programs other RGNs are pursuing. I am not the in-depth expert on each of these projects and their nuances and subtleties. If one of these projects piques your interest. I can connect you to that RGN for more detailed and comprehensive information.

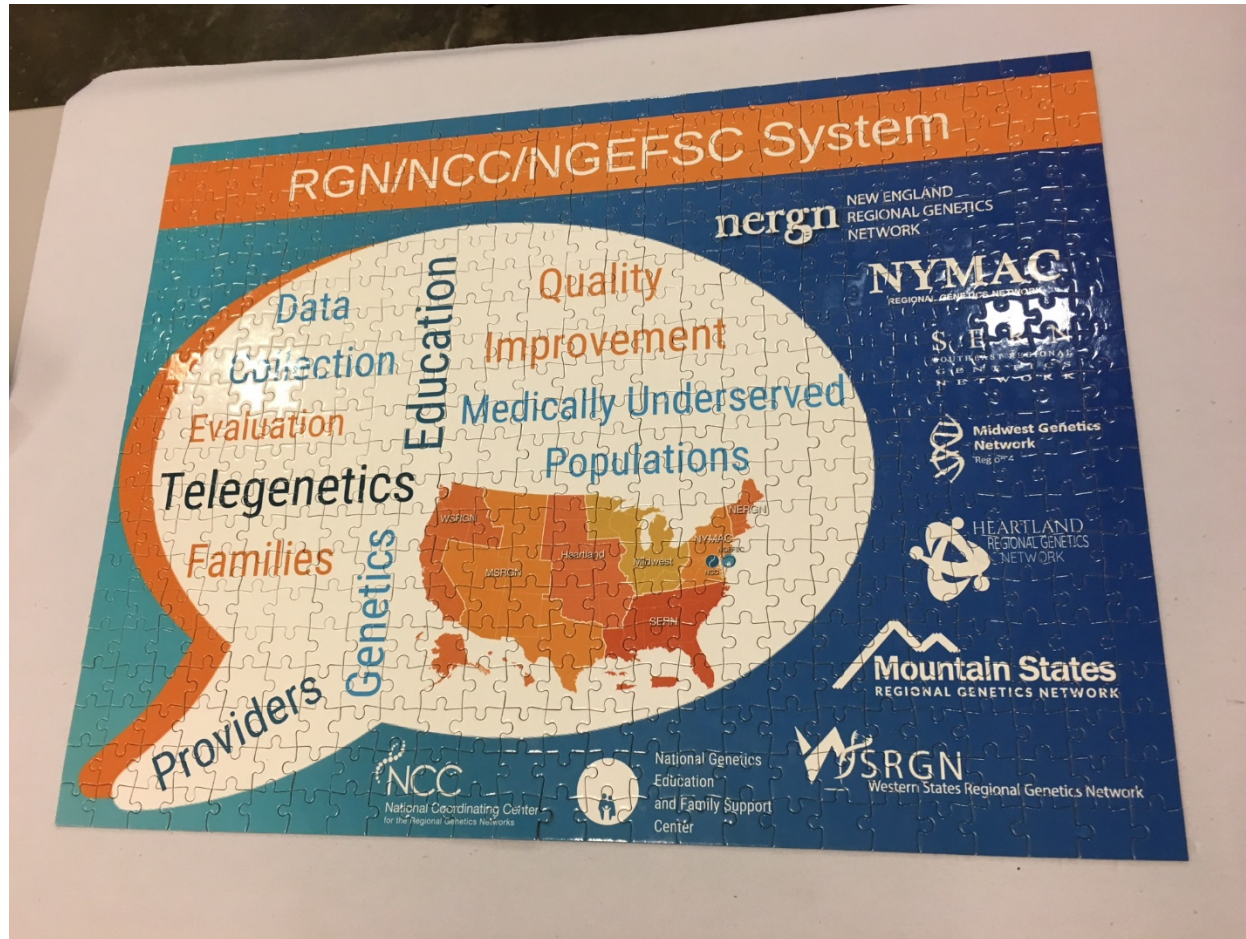
What are the major stops on this tour?



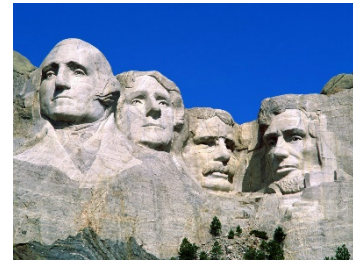
- 7 Regional Genetics Networks
- National Coordinating Center
 - Housed at ACMG
- National Genetics Education and Family Support Center
 - Housed at Genetic Alliance
 - Partnered with Family Voices

All supported by HRSA

Great travel companions make traveling easier and so much fun



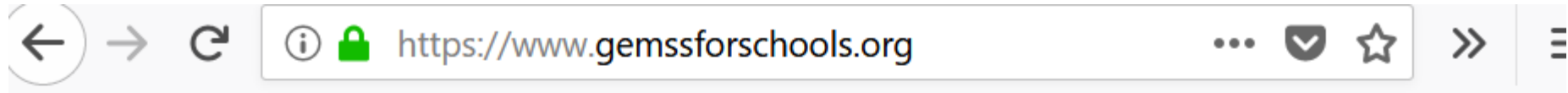
The Major Landmarks and Sights on Tour



- The **purpose** of the RGNs is to: 1) **link medically underserved** populations (based on poverty, rural geographic location, and/or populations that experience health disparities) to genetic services; 2) implement **quality improvement** activities to increase the connection with genetic services for the medically underserved; 3) implement evidence-based innovative models of **telehealth** and/or telemedicine with a focus on clinical genetics outreach; and 4) **provide resources** to genetic service providers, public health officials and families.



NERGN



Menu

Family Voices staff training and support—2 in-person trainings (expanding to 4 more). Provided background information on genetics and training on available resources.

WSRGN



Telehealth training –across the country with all RGNs (varying levels of financial support from other regions)

- WSRGN trained 15 GCs, 1 intern

- NERGN trained 14 GCs, 22 GC students, training scheduled for year 2.

- MSRGN—1 Geneticist, and 2 GC program faculty

- Heartland— trained 9 GCs, co-leading the training, focused on training geneticists

* Looking in to adding language interpretation in telemedicine in year 2.

NBS fact sheets for families, newbornscreening.info—new fact sheets for Fabry, X-Ald, Gaucher, MPS1

NBS Education Videos—develop series of short educational whiteboard videos related to NBS and NBS hearing screening targeted at the general population and PCPs.



SERN

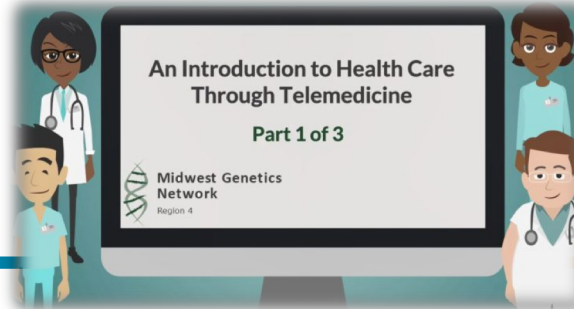


Telehealth outreach clinics—working to establish outreach clinics in 3 states: GA, LA, and SC.

Electronic Genetic Nutrition Academy (eGNA)—Dietitian-focused clinical and nutrition management educational modules providing evidence-based knowledge about inherited metabolic disorders. Live training webinars (include case conferences, journal clubs).

Lunch and Learn—in-person and webinar series available to healthcare providers, lab personnel, clinicians, genetic counselors, public health staff, and students. Held 2 webinars with 47 in-person and 36 via webinar.

MGN



MOC4 Module on Newborn Screening— QI program required for maintenance of certification by physician specialty boards developed by Midwest. It was launched for pediatricians through a collaboration with the MN AAP, and was utilized by 90 physicians on its first offering. Will be offered a second time next month and will be available to pediatricians from other regions. The region is also working on a second MOC4 module on genetic testing for developmental delay and autism, and hope to make it available for pediatricians, family physicians, and general internists. A champion from the MN AAP has been central to this project's success.

Telegenetics Primer Video— 3 short videos aimed at patients and families to help them prepare for a first telemedicine visit.

<https://midwestgenetics.org/resources/telemedicine-resources/>

Telehealth Training—trained 10 providers at a spring telemedicine training hosted by Heartland.



NYMAC



Toll Free phone line—live in August, available for patients to connect them to genetic services in their area.

Red Flags for PCPs—red flags document targeted to Community Health Centers to increase number of patients connected to genetic services. Delivered as part of in-person and webinar presentations.

Telehealth partnership with CHC and Johns Hopkins—outreach clinic to CHCs in Maryland.

Telehealth Community of Practice—online and remote support by a telehealth champion to support efforts including training; online community populated with resources and tools for clinicians. Provider to provider consults.

Heartland



Marshallese/Hispanic Latino/Native American-American Indian Education Project—developing targeted education materials (videos, written), leading workshops/community gatherings (focus groups), translating materials into Marshallese and Spanish.

Education for Families and Home Visitors—providing education materials (videos, written), workshops/training conferences to increase knowledge about accessing genetic services.



NCC

Healthcare Interpreter Network — Prenatal completed, 480 healthcare interpreters have received the train-the-trainer training, the module will be on the NCC website along with a listing of healthcare interpreters who've completed the training and may provide it. Ms. Roat worked with MSRGN on the first training. Currently the pediatric module is under development.

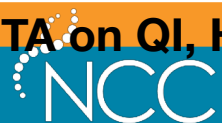
ACT Sheets — Clinical Decision support tools on genetic conditions for PCPs. Working on newly added conditions to the RUSP, secondary findings, and Non-invasive prenatal screening.

Clinical services directory — vendor and hosting mechanism settled, beginning the requirements process now, will develop local instances with RGN branding for each RGN, a centralized mechanism will allow RGN staff and NCC staff to update.

CQ State Tracker — National resource of information for tracking state, regional, and national legislation and policy development related to genetic services. Available on NCC website.

Telehealth Guidelines project with ATA, NSGC, and ACMG

TA on QI, Healthcare Access and Financing



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NGEFSC

Family-Led Organization Guides (RGN specific)—NGEFSC developed RGN-specific guides that connects RGNs and families to their regional and state-based family-led organizations.

Advocacy Atlas—cross-linking web resource that serves as a compendium of resources for navigators, home care workers, nurses, etc. to share with families.

Diseaseinfosearch.org –web resource containing information for families on support groups, providers, and resources. Currently building web connections to lab reports, personal health records, other educational websites, and to be used by care navigators and family support services.



Recap of Major Landmarks and Sights

Medically Underserved Connection to Genetic Services

- Toll Free call line (NYMAC)
- Healthcare Interpreter genetics education modules (1. Prenatal, 2. pediatric) (NCC)
- Marshallese/Hispanic latino/American Indian Education Project (heartland)
- Home Visitor Education (Heartland)
- Family Voices Genetics Training (NERGN)
- Education Videos (WSRGN)
- Telehealth Education Videos (MGN)
- MOC Part 4 Newborn Screening (MGN)

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Telemedicine:

- Telehealth consultation (NERGN)
- Telehealth clinical services (heartland MSRGN)
- Telehealth education videos (MGN)
- Telehealth training—
WSRGN/Heartland training
 - NERGN, MGN, SERN, NYMAC,

Resources:

- NBS Fact Sheets (WSRGN)
- GEMSS (NERGN)
- Red Flags (NYMAC)
- ACT Sheets (NCC)
- Clinical Services Directory (NCC)
- CQ State Roll Call (NCC)
- Advocacy Atlas (NGEFSC)
- Family-led Organization Guide (NGEFSC)

Mid-Trip Adjustments and Post-Trip Mementos

Making sure we document and share what we've learned and done on this 3-year journey

The RGNs, NCC, and NGEFSC participate in self-determined QI projects focused on 1) establishing a framework of QI throughout each project (training RGN staff, providing TA, and helping set up QI projects as needed); and 2) evaluating the overall system through HRSA-developed national performance measures.

Need More Information? NCC is the RGNs' AAA, we've got your trip tix.

Michael S. Watson, MS, PhD,
Project Director,
mwatson@acmg.net

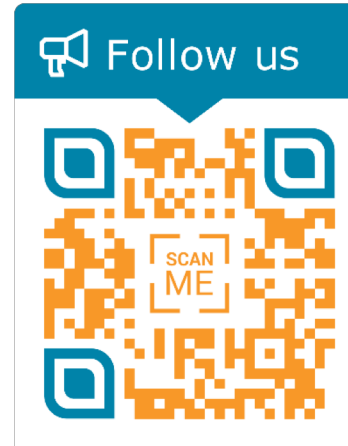
Alisha Keehn, MPA,
Associate Project Director,
akeehn@acmg.net

Megan Lyon, MPH,
Project Manager,
mlyon@acmg.net

Debbie Maiese, MPA,
Evaluator, dmaiese@acmg.net

Sanjyot Sangodkar, MEM,
Administrative Assistant,
ssangodkar@acmg.net

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Thank you!!!!

