Cross-Country Tour: Highlighting Exciting Projects from Across the NCC/NGEFSC/RGN System

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NCC, serving as a RGN Project Tour Guide
(Certification pending)
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I am going to take you on a little RGN Project Highlights tour....
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, MCHB, GSB
Great travel companions make traveling easier and so much fun.
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.
Family Voices staff training and support—2 in-person trainings (expanding to 4 more). Provided background information on genetics and training on available resources.
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

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.
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.
Developmental Delay Genetic Testing Algorithm—guide a PCP through the initial genetic testing indicated for a child with developmental delay prior to the first visit with a geneticist. (in draft stages, also including a section on legal protections against genetic discrimination, non-genetic causes of developmental delay)


Indian Health Service Webinars—providing information to Indian Health Service PCPs that will facilitate referral. (one webinar to date, future calls to be held quarterly).

State teams Model—Developed state teams comprised of clinicians, public health professionals, and consumers from all states in the region. These state teams help develop, review, launch, and provide feedback on projects within MSRGN. They meet monthly and in-person annually.

Telehealth Training—training 5 providers per year. Working to develop telemedicine clinics in WY and UT.
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.

**Co-leading telemedicine training with WSGRN**
Healthcare Interpreter Network (yesterday’s presentation)—Prenatal completed and Year 2 Pediatric will be completed.

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, will begin the mapping work in October and then will develop the bi-directional linkage to RGN directories and provide local instances for those RGNs wanting to utilize the NCC directory.

CQ State Roll Call—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
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.

Engaging families Family Voices training
Advocacy ATLAS

...Accessible Tools for Leadership and Advocacy Success

NCC
National Coordinating Center for the Regional Genetics Networks
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)
- Genetic Testing Algorithm (MSRGN)
- IHS Webinars (MSRGN)
- State Team Model (MSRGN)
- Marshallese/Hispanic latino/American Indian Education Project (heartland)
- Home Visitor Education (Heartland)
- Family Voices Genetics Training (NERGN)
- Education Videos (WSRGN)
- eGNA Case Conference/Journal Club (SERN)
- Lunch n Learns (SERN)

**Telemedicine:**

- Telehealth consultation (NERGN)
- Telehealth clinical services (heartland, MSRGN)
- Telehealth training—WSRGN/Heartland training
  -- NERGN, MSRGN, 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 (NGEFS)
- Family-led Organization Guide (NGEFS)
- DiseaseInfoSearch (NGEFS)
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.

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Thank you!!!!