Improving Services for Individuals with Genetic Conditions
• Genetic Alliance
  o Founded in 1986
  o Engaging individuals, families, and communities to transform health

• American College of Medical Genetics & Genomics (ACMG)
  o Funded by Genetics Services Branch of the Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA)
    • National Coordinating Center for the Regional Genetics Services Collaboratives (NCC) (2004-Present)
About the Effort

• Current regional genetics collaboratives funded by GSB until 2017 ([www.nccrcg.org](http://www.nccrcg.org))

Our Task

• Conduct national needs assessment
• Propose a framework for a model for “regional genetics care centers”
Guiding Factors

Framework should:

- Align with national/regional needs
- Be supported by evidence
- Improve access to **genetic services**
  - What do we mean by genetic services?
  - What are the current gaps/barriers to services?
    - NGECN: What do families need most?
  - What are the areas for the most measurable impact?
About Today’s Participants

Live Poll: Which term best represents the hat you’re wearing on today’s call?

• Leader of support/advocacy organization
• Individual with genetic condition
• Parent/Family member of individual with genetic condition
• Public Health Professional
• Other
HRSA Perspective

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Health Resources and Services Administration
Maternal and Child Health Bureau
Division of Services for Children with Special Healthcare Needs
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Genomic Medicine

To optimize the impact of genomic discoveries, advances need to be integrated into activities that directly influence the health of the public
Entry Points into Genetic Services

- Infertility
- Multiple SABs
- Family history
- Carrier screening
- Prenatal screening/ diagnosis
- Newborn screening
- Major/minor malformations
- Screening for growth, neurocognitive development, autism, hearing, vision
- Family history
- Pediatric cancers
- Adolescent and early adult onset degenerative conditions
- Family history
- Adult onset degenerative conditions
- Hereditary cancer, cardiovascular
- Common complex disorders
- Family history
Prerequisites for Genomic Medicine

• Evidence, value, outcomes

• Systems of Genetic services
  – Healthcare provider literacy, guidelines, clinical decision support tools to:
    • Identify, test/refer, communicate and use genomic information in treatment decisions
  – Genetic providers
    • Delivery models to reach everyone who needs services regardless of where they live or the family born into
  – Payment

• Systems of care for individuals and families
Regional Genetics Service Collaboratives (RCs)

Provide a regional infrastructure of public health genetics to improve, expand, and evaluate access to a system of genetic services and the quality of those services to improve health outcomes for children, youth and adults across their lifespan.

National Coordinating Center - ACMG

1. NEGC: New England Genetics Collaborative
2. NYMAC: New York-Mid-Atlantic Consortium
3. SERC: Southeast Regional Collaborative
4. Region 4: Region 4 Genetics Collaborative
5. Heartland: Heartland Regional Genetics and Newborn Screening Collaborative
6. MSGRCC: Mountain States Genetics Regional Collaborative
7. WSGSC: Western States Genetic Services Collaborative
National Genetics Education and Consumer Network (NGECN)

• Led by Genetic Alliance

• Goal: Build a network of partnerships and tools that improve consumers’ education about and access to genetic services, as well as improve the quality of those services

• Focus on consumer engagement in the RCs, supporting consumer-focused initiatives and groups, and public education
Regional Genetic Services Collaboratives

- Develop partnerships to leverage resources and collaborate on solutions
- Identify geographic, population, and funding challenges to accessing genetic services and pose and test solutions
- Pilot projects, data collection related to genetic services
- Development of policy papers and forums to guide the development of services and insurance coverage
New paradigm of regional genetic services?
Going Forward

• What are the gaps that a public health approach can address?
• What are the failures in the market that HRSA can help address?
• Who needs genetic services that aren’t getting it?
• What is the needle we are trying to move?
• What will be the impact if we succeed?
Contact Information

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Understand Gaps in Access and Quality

- Survey Eligibility
- Demographics
- Identification
- Finding Services, Information, and Support
- Accessing Care, Services, and Support
- Adult Care
- Beyond the Clinician’s Office
Demographics

Screener question: Has a doctor or other health care provider ever told you that you (or your child) has a genetic condition?

☐ Yes
☐ No
Demographics, Cont.

- State of residence (regions)
- Birth year of affected individual
- Genetic condition(s)
- Year genetic condition was confirmed

- Other demographic questions of interest/importance to you and your community? Please enter into chat box.
Identification

How long was it from when you/your child first started having symptoms till the time of diagnosis?  
Live poll: Audience please enter estimated length of time into chat box.

What/who helped most in finding a diagnosis for yourself/your child?  
• PCP  
• Genetic Counselor  
• Geneticist  
• Online information  
• Support group  
• Clinical trial/study

Live poll: Are there other people/resources that you used? Please enter into chat box.
Identification, Cont.

After genetic testing, what were the biggest questions you had?
Live poll: Please enter your suggestions for what the most popular responses would be.

Other issues around identification?
Finding Services, Info, Support

How do/did you select your/your child’s specialists?

- Recommended/referred by other provider
- Online information about the provider
- Recommended by support group
- Recommended by other parents

Live poll: Are there other ways that helped you determine the specialty providers you/your child sees for a genetic condition? Please type into chat box.
Finding Services, Cont.

How do you rank the following factors when choosing a specialty provider?

- Travel distance
- Insurance coverage/anticipated out of pocket costs
- Reviews/ratings from an online source
- Reviews/ratings from a friend/peer

Live poll: Are there other factors that influence how you choose a specialist? Please enter into chat box.
Finding Support

How did you get connected to a support person or group?

• Searched online
• Referred by a provider
• Friend/word of mouth
• Social media
• Other: please specify
• Not applicable

Live poll: Are there other ways you got connected to a support person or group? Please type into chat box.
Finding Support, Cont.

What types of support or information do you receive from a support group? (Check all that apply)

• Support and peer matching/advice from others with similar conditions
• Therapy and counseling/emotional support
• Medical referrals
• Legal advice
• Financial assistance
• Research involvement and clinical trials
• Information and education
Finding Information

What types of information have you had trouble finding?

- Information about what is and what is not covered
- Where to find providers
- Information about quality/who are the best providers?
- Information about tests and treatment
- Condition information
- Information about other types of services/support
- Information about research/clinical trials
- Other, please specify:
Accessing Care, Services, & Support

What is your biggest barrier in accessing genetic services?

- Distance
- Cost
- Availability of appointment
- Lack of referral
- Lack of time/other more pressing needs
- Don’t know what you need
- Don’t know where to find
- Lack of providers you like/trust
- Don’t know

Live Poll: Are there other major barriers you have experienced related to genetic services? Please type into chat box.
Accessing Services

During the past 12 months how hard was it to access the following services/supplies? (Not hard, Hard, Very hard, Don’t know, Not applicable)

- Medical foods
- Genetic counseling
- Genetic testing
- Specialists visits
- Drugs
- Surgeries
- Medical transport
- Medical supplies/equipment
- Preventive care (well visits, etc.)
- Care coordination
- Nursing/home healthcare services
- Social/emotional support
- Mental health services
- Therapies (physical, occupational, behavioral, etc.)
- Lab services
Accessing Services, Cont.

What was the biggest barrier to receiving these services?

- Insurance coverage
- Distance to receive services
- Availability
- Lack referral
- Lack of quality
- Time to approval
- No barriers

Live poll: Are there other big barriers that we haven’t thought about? Please type into chat box.
Accessing Care

How often do you have to travel over 1 hr to receive care?

Live Polls:
What minimum amount of travel time constitutes a significant burden for families (for each visit)?

- 1 hr
- 2-3 hrs
- Half a day
- Full day
- 2+ days
What solutions would you suggest to minimize the distance and time burden to receiving care?

• Telehealth with your PCP
• Telehealth visit with genetic service provider
• A longer drive to a genetics specialist center where you could receive comprehensive care in one day
• A clinic day for my/my child’s condition

Live Polls:
Would families know the term “telehealth”? Please suggest other solutions in to chat box.
Which of the following support services would you find most helpful in navigating your/your child’s care?

- Making appointments
- Appointment reminders and/or rescheduling
- Virtual emotional support and guidance
- In-person emotional support and guidance
- Recommendations for local genetics and medical professionals
- Training/advice on being an effective advocate
- Help understanding insurance and tax benefits
- Other: please specify
Accessing Care: Navigation/Coordination

If a navigator/care coordination was available, which type would you think would be most useful? (1 most useful, 6 least useful)

• A fellow parent
• A care coordinator within your physician’s office
• A care coordinator at an insurance company
• A support or advocacy organization recommended by the clinic
• List of available services
• A telephone helpline
• Other: please specify

Assuming your insurance remains the same, what would help you navigate the current system better?

• A tool to make appeals more easily
• Someone to help explain the appeals process
• Better comparisons/information on quality
Navigating the Current System

Assuming your insurance remains the same, what would help you navigate the current system better?

• A tool to make appeals more easily
• Someone to help explain the appeals process
• Better comparisons/information on quality

Live Poll: Are there other resources that would help you and other families navigate the system better? Please type into chat box.
Adult Care

What are the biggest issues you/your child face around finding adult care for a genetic condition?

Live Poll: Tell us what issues you/your community faces accessing adult care, if any. Please enter into chat box.
Beyond the Clinician’s Office

What factors impact your decision to participate in a registry the most?

• Knowing my information will be kept safe
• Who the information is shared with
• What the information will be used for
• Who owns the registry
Where can we make the greatest impact?

We need your help.

- Complete the webinar evaluation and provide your thoughts on these questions and other areas of need for families.

- Send your thoughts and feedback to Sharon Romelczyk, Program Manager at sromelczyk@geneticalliance.org.

- Join the Genetic Alliance Family Advocates Network to stay engaged on this topic: GeneticAlliance.org/about/mailinglist.
Next Steps

• Provide your review on updated draft of needs assessment questions, following this webinar

• Help us collect valuable national data by disseminating the final needs assessment to your members/families you work with (expected September 2015)