



# Improving Access to Genetic Services for Underserved Populations- *Updates from the NCC* Megan Lyon, MPH

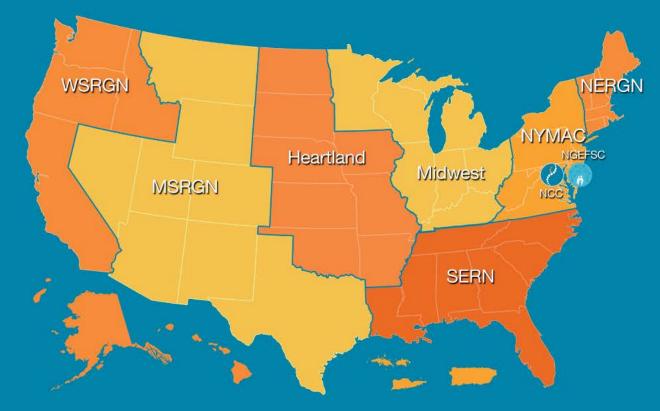
**Co-Project Director, NCC** 

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This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

**Nission** 

Funded by the Health Resources and Services Administration (HRSA), the Regional Genetics Networks (RGNs), the National Coordinating Center for the Regional Genetics Networks (NCC), and the National Genetics Education and Family Support Center (NGEFSC or Family Center) mission is to improve access to genetic services for underserved populations.



# Core Focus Areas of NCC



### Genetics and Genomics Education



### Telegenetics



Data Collection and Evaluation



Genetics Policy Education

# Genetics and Genomics Education 2023 Updates



for the Regional Genetics Networks

### ACT Sheets and Algorithms



acmg.net/act

### Clinical decision support tool for non-genetics providers.

### **New Updates**

### **ACT Sheets**

- 24 Updated ACT Sheets
- 4 New ACT Sheets
- 24 Updated Algorithms
- 8 New Algorithms

ACMG	ACT She
Ceremon and Centering	
Newborn Screening ACT Sheet	
[Increased Leucine]	
Maple Syrup Urine Disease Differential Diagnosis: Maple syrup urine disease (MSUD); hydroxyprolinemia.	
You Should Take the Following IMMEDIATE Act	ions:
<ul> <li>Inform family of the newborn screening result</li> </ul>	
<ul> <li>Ascertain clinical status (poor feeding, vomitie)</li> </ul>	
<ul> <li>Consult with pediatric metabolic specialist the</li> <li>Evaluate the newborn for signs of poor feedin seizures. If any of these findings are present treatment in consultation with the metabolic</li> </ul>	
<ul> <li>Initiate confirmatory/diagnostic testing and n</li> </ul>	
<ul> <li>Provide the family with basic information ab</li> </ul>	out MSUD, including dietary management.
Report final diagnostic outcome to newborn s	creening program.
seizures, coma, cerebral edema, irreversible development	f cerumen. If untreated, the condition will rapidly progress to tal delay, and possibly death. Individuals with variant forms ater in infancy or childhood but remain at risk for severe
Additional Information:	
How to Communicate Newborn Screening Result Emergency: Protocols (New England Consortium o Gene Reviews Meetine Plus	is el Metabolic Programat
Condition Information for Families-HRSA Newb	om Screening Clearinghouse
Referral (local, state, regional, and national):	
Find a Genetics Clinic Directory Genetic Testing Resistry	
aubly denoted to districting the same results to determining the property of any quell's preve ances primerical by the individual patient is inputton. Classical are representinged to denote the managers (Classical and any Arthur to the sortion of the last to be prevent wave and advances	Objique la fugi time porteta quelle anche a series. Subserse in tta più tite mano in segn della supplementa inclusioni di dipopoi avvoluene and tanto e estitutione ai distripermettere and tant Rece e tella discoste divide all'apple più te da fue contratte di popoi in tella questita di andi Quella contratta di applementa di applementa di applementa di applementa di applementa di Quella contratta di applementa di applementa di applementa di applementa di applementa di applementa quella contratta di applementa di applementa di applementa di
provided to consider whether indefaction property indepeth team ratio if the performance of m	minim hads and allow providence.



Animated CME Video to accompany ACT Sheets:

SMA , X-ALD, MPS I available now



Healthcare Interpreter Training



https://nccrcg.org/he althcare-interpreterresources/

### **New Updates**

In addition to the trainings NCC supports, the healthcare interpreter training program has been expanded to include a new curriculum (Interpreting for Cancer Genetics) and we have published the curricula glossaries in nine languages.



### Other Educational Activities



https://nccrcg.org /educationalmodules/



# Medical Necessity Webinar Series



### **Genetics Workshop for PAs**

Available online through AAPA



#### Evidence-Based Guideline Webinar Series First One Available Now!



## Resource Repository



https://nccrcg.org /resources/



# Genetics Policy Education



# Policy Website



geneticspolicy. nccrcg.org



Policy Resources



geneticspolicy. nccrcg.org

- 300+ Proposed Legislation/Regulation
   Tracked
- 54 State Medicaid Genetics Programs
- 25+ Policy Areas
  - Including policy statements from national genetics organizations.
- General Policy Resources

Genetics Policy Hub GPH Webinar Series



#### bit.ly/gphwebinars

Every other month, the GPH Webinar Series is held to discuss popular genetics policy topics.

Join us every other month webinar series that shares the latest genetics policy information from across the United States and includes invited speakers who provide real-world experience with the genetics policy.

**Genetics Policy Hub Webinar Series** 

#### Genetics Privacy- May 19, 2023

GPH

On May 19, 2023, the Genetics Policy Hub, in celebration of Public Health Genetics and Genomics Week, will hold our next GPH Webinar Series about the latest policy information related to genetics privacy. The webinar will:



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# Workforce Assessment Efforts



Assessing the Genetics Workforce



### This spring, NCC published *The 2019 medical genetics* workforce: A focus on laboratory geneticists.





Genetics

Check for

<sup>1</sup>American College of Medical Genetics and Genomics, Bethesda, MD; <sup>2</sup>Medical College of Wisconsin, Milwaukee, WI; <sup>3</sup>American Board of Medical Genetics and Genomics, Rockville, MD; <sup>4</sup>Johns Hopkins School of Medicine, Baltimore, MD

ARTICLE INFO	ABSTRACT
Article history:	Purpose: The aim of this report is to inform the genetics and genomics field about the results of a
Received 6 September 2022	2019 workforce survey of US laboratory geneticists.
Received in revised form	Methods: The American Board of Medical Genetics and Genomics distributed an electronic
21 March 2023	survey to board-certified/eligible diplomates in 2019. Analysis of the responses was performed



Assessing the Genetics Workforce

2023 Effort

### Objective

Disseminate a workforce survey in 2023 to geneticists, metabolic dietitians, genetic nurses, and physician assistants to assess the capacity of the workforce.

### Questions

Demographics Position Characteristics Practice Characteristics

### **Surveyed Providers**

- Geneticist
- GeneticCounselors
- Genetic Nurses
- Genetic PAs
- MetabolicDietitians

# Other Major Activities of the NCC



"Find a Genetics Clinic" Directory



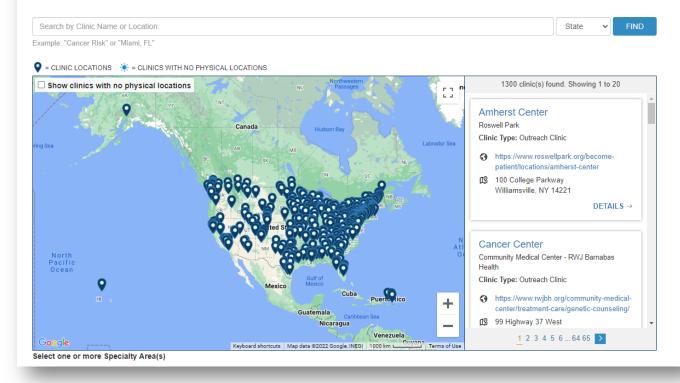
clinics.acmg.net



HOME SUBMIT CLINIC CONTACT ACMG

#### Find a Genetic Clinic

ACMG's "Find a Genetics Clinic" allow individuals to search for genetics clinics across the United States. The directory contains the locations of genetics clinics that have requested to be listed.





### Contact Us



#### nccrcg.org



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