

Family Leadership Resources and Opportunities within the Genetics Network

**2022 EARLY HEARING DETECTION & INTERVENTION
VIRTUAL CONFERENCE**

March 14, 2022



This is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$400,000 with 0 percent financed with nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit [HRSA.gov](https://www.hrsa.gov).



HRSA DSCSHN: Program Snapshot

Systems of Care

Medical home

Transition

Financing

Family/Professional Partnership

CSHCN Research Network

CMC CoIIN

Screening

Newborn screening

Genetics Programs

Vision

Early Hearing Detection and Intervention

Environmental Health

Condition-specific

Epilepsy

Autism

Hemoglobinopathies

Hemophilia

HRSA-Funded Genetic Programs



- National Genetics Education and Family Support Program (Family Center)
- Seven Regional Genetics Networks (RGNs)
- National Coordinating Center for the Regional Genetics Networks (NCC)



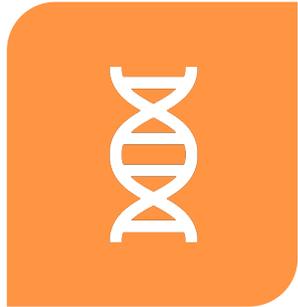
National Genetics Education and Family Support Center



Linking families to genetics



Program Goal: Ensure that all individuals and families who have, or at-risk of having a genetic condition:



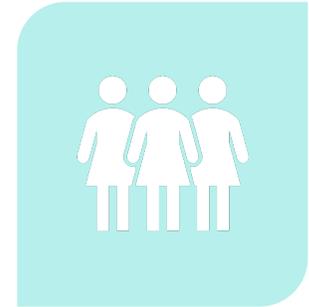
Understand the implications of a genetic diagnosis



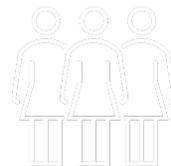
Have access to genetic services



Be engaged in their own care



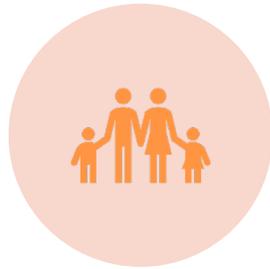
Have opportunities to engage in a meaningful way in national, regional, and local genetic healthcare delivery system



Family Center Approach



**Identifying, promoting, and
maintaining online
resources**



**CREATING OPPORTUNITIES
FOR FAMILY ENGAGEMENT**



**CONDUCTING STAFF AND
FAMILY TRAININGS**



**Connecting family
organizations with NCC and
RGNs**



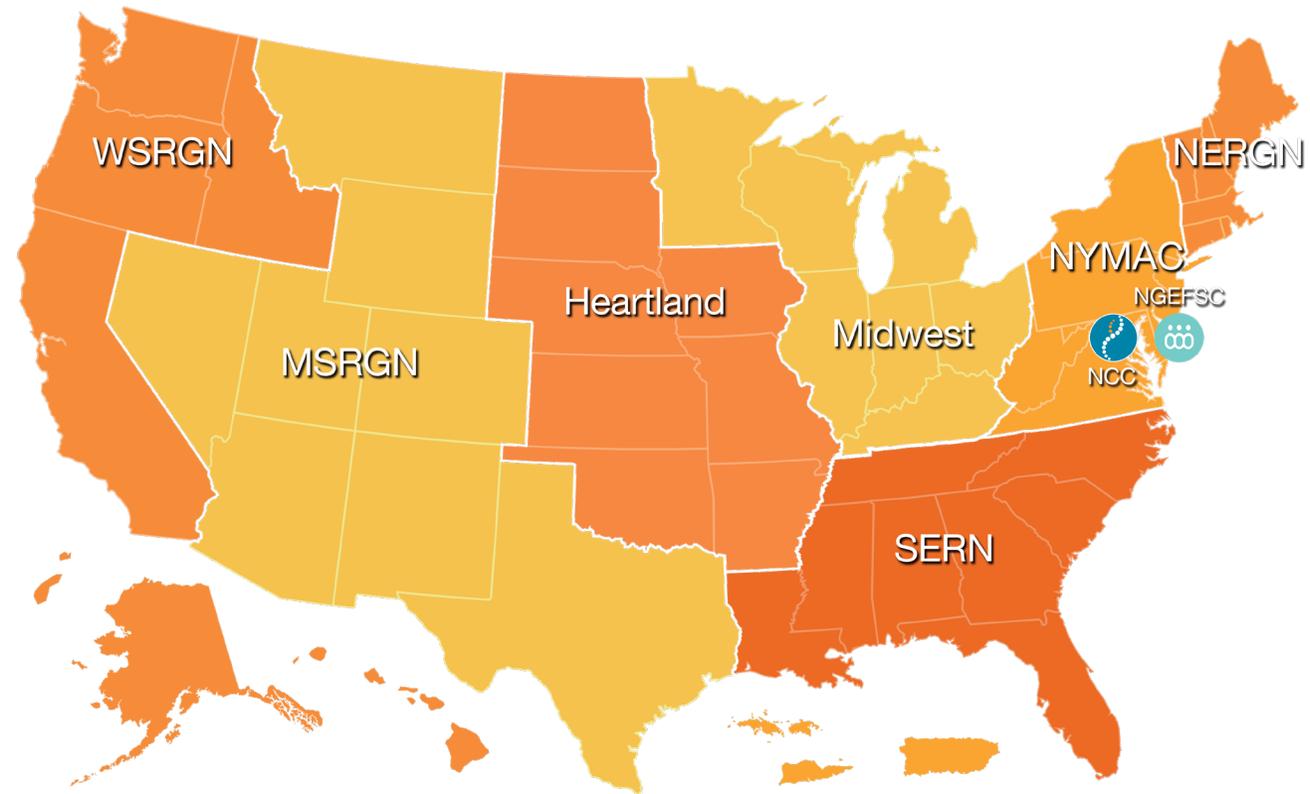
NCC

National Coordinating Center
for the Regional Genetics Networks

- Resource Repository
- Find a Genetic Service
- Policy Hub



Find Your RGN – NCCRCG.ORG



NYMAC FAMILY ENGAGEMENT

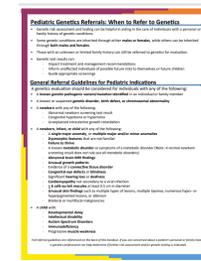


- Working with The National Genetics Education and Family Support Center
- Supporting educational and resource needs
- NYMAC Annual Meeting speakers, topics, encouragement of collaboration
- Engaging our F2Fs and P2Ps and Family Voices
- Feedback on logo, website, social media, resources, meeting topics, etc
- Jurisdiction Team members and co-leads
- Advisory Committee Members
- Reciprocal project engagement (FV TCoP)
- Please reach out to us to learn more and get involved!! NYMAC@ferre.org



[Genetic Screening Resources for Families | Heartland Genetics Services Network \(heartlandcollaborative.org\)](#)

[Patients & Families - NYMAC \(nymacgenetics.org\)](#)



[When to refer patient to Genetics | NYMAC | Regional Genetics Network \(nymacgenetics.org\)](#)

Also available in Spanish



[Your Genetics Appointment – YouTube](#)

Also available in other languages



[Recursos genéticos en Puerto Rico \(Genetics Resources in Puerto Rico\) - NYMAC - Regional Genetics Network \(nymacgenetics.org\)](#)

EXPANDING ACCESS TO GENETIC SERVICES
Sharing Strategies - Finding Solutions

April 5 & 6, 2022
8am-4pm daily

Two-Day Interactive Virtual Annual Conference

Engage with families, advocates, health professionals, and other stakeholders in a dynamic dialogue about barriers to care for underserved populations, diverse models of genetic services, and genetics in public health. Actively collaborate to identify strategies and solutions to improve access to genetic services.

- Spanish Language Interpretation
- Closed Captioning
- Industry Lectures

Free CME / CEU were awarded for the 2021 Annual Conference

View the agenda and learn more: <https://nymacgenetics.org/nymac-annual-meeting-april-5th-6th-2022/>

Advocacy and Support Resources
Basic Genetics
Family History
Newborn Screening
Getting a Diagnosis
Genetic Testing
Medical Information about Genetic Conditions
Care Coordination and Medical Home
School and Support Resources
Emergency Preparedness
Insurance and The Affordable Care Act
Telemedicine Resources for Families
Parent Corner

[NYMAC Annual Meeting - April 5th & 6th, 2022 - NYMAC \(nymacgenetics.org\)](#)



Opportunities for Involvement



Inform

Stay up to date on the latest events, resources, and trainings by signing-up for updates or follow organizations on social media.

Connect

Connect with your local RGN for regional opportunities.

Reach out

Reach out at mmartzke@expectinghealth.org



Stay Connected

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National Genetics
Education and
Family Support Center