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All Abroad the Genetics Access Tour

An Overview of the RGNs and NCC

Megan Lyon, MPH
NCC Associate Project Director

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Mission

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

Family Engagement and Leadership



Genetics and
Genomics
Education



Telegenetics



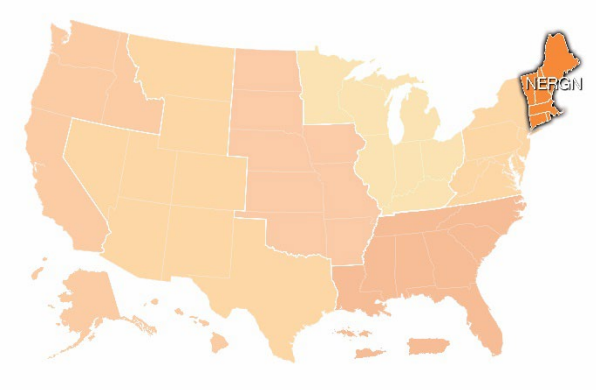
Data
Collection and
Evaluation



Genetics
Policy
Education

A Tour through the RGNS-


Genetics and Genomics Education



Genetics Education Series

<https://www.negene-tics.org/professionals>

[FIND A CLINIC](#) [CONTACT US](#) [SEARCH NEW ENGLAND REGIONAL GENETICS NETWORK](#)


 **NEW ENGLAND
REGIONAL GENETICS
NETWORK**

[Home](#) [About Us](#) [GEMSS](#) [Families](#) [Professionals](#) [Resources](#)

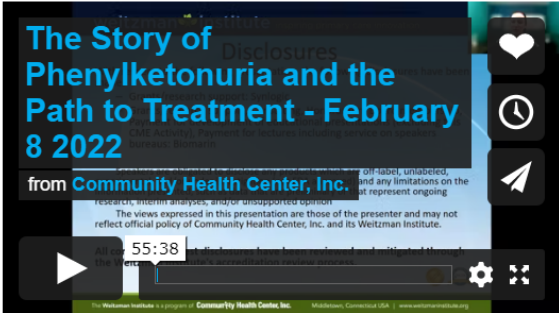
Genetic Webinars

In collaboration with Weitzman Institute, NERGN offers free genetic webinars. View video recordings from past sessions on this page. Attend one or all. Free continuing education credits are available if you attend a live event.


Stay tuned for our next live sessions, starting in the fall of 2022.



School-Aged Patients with Genetic Disorders

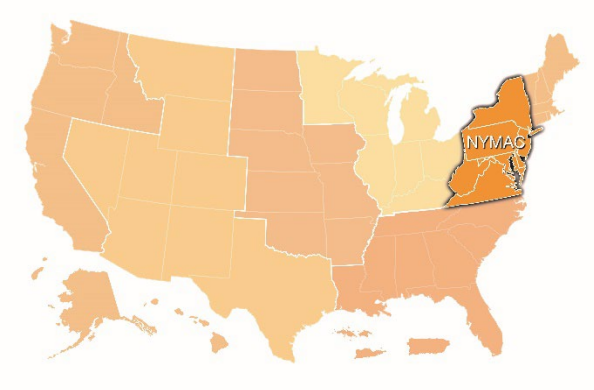


PKU and the Path to Treatment



Financial Aspects of Genetic Testing

Free online modules that cover condition specific topics to general genetic topics.



When to Refer to Genetics

<https://nymacgenetics.org/providers/when-to-refer-patient-to-genetics/cancer-genetics-referrals/>

Cancer Genetics Referrals

[Home](#) / [Providers](#) / [When to refer patient to Genetics](#) / [Cancer Genetics Referrals](#)

The cancer referral information on this page is also available as a flyer in pdf format.

[DOWNLOAD PDF \(ENGLISH\)](#)

[DOWNLOAD PDF \(ESPAÑOL\)](#)

+ [When to Refer to Genetics](#)

Resources for Providers

[Providers](#)

[Telemedicine and Telegenetics](#)

[Insurance and Genetic Discrimination](#)

[Educational Events and Opportunities for Providers on Genetics Topics](#)

[Medical Information about Genetic Conditions](#)

“When to Refer Genetics” walks a healthcare professional through guidelines and recommendations on genetic conditions related to prenatal, pediatric, and cancer genetics.



electronic Genetic Nutrition Academy (eGNA)

<https://egeneticnutritionacademy.org/>



[eGNA](#)[About](#)[FAQ](#)[Submit Abstract](#)[Register](#)[Map](#)[Donate](#)[Contact](#)

LOGIN

| eGNA | |
|-------------------|---|
| What is eGNA? | eGNA (electronic Genetic Nutrition Academy) is a free, web based system of educational modules providing evidence-based knowledge about nutrition management for inherited metabolic disorders. |
| Intended Audience | Genetic metabolic dietitians and other clinicians |
| 2018-2021 | All Metabolic Disorders |

Sample Course Materials

Medical Commentary from eGNA Session 6 with Elizabeth Krupinski, PhD. The session topic was Telemedicine.

S

eGNA Session 6 - Telemedicine - Medic...

Watch later

Share

ADMINISTRATIVE & REGULATORY ISSUES

- Regulatory
 - Malpractice
 - Licensure & Credentialing
 - Standard of Care
 - Ryan Haight/Prescribing
- Administrative
 - Protocols and procedures
 - Workflow
 - Economic models (Billing and re-imbursement)



Educational modules about nutrition management for inherited metabolic disorders.



**Midwest Genetics
Network**
Region 4

On-Demand Learning

<https://midwestgenetics.org/continuing-education-opportunities/>

On Demand Learning Opportunities

Increasing Access to Care Through The Lens of Equity and Inclusion

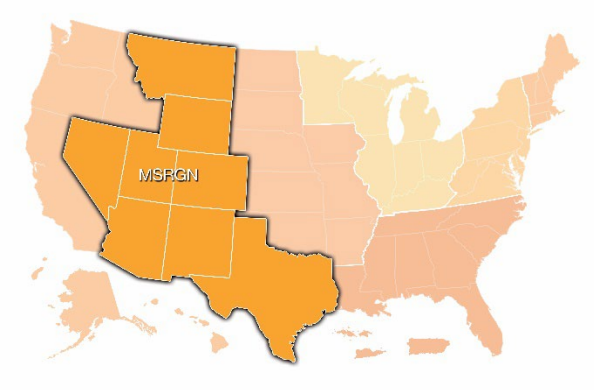
Learn how Implicit Bias and Gender Diversity can impact care and genetic counseling and earn **FREE** PRA Category 1 CME credits

Key Audiences

- Genetic Counselors
- Genetic Counseling Students
- Genetics Providers
- Medical Residents
- Primary Care Providers
- Medical Students

[Additional Details](#)

Free online modules that cover condition specific topics to general genetic topics.



Red Flags 4 Genetics

SEÑALES DE ALARMA SOBRE GENÉTICA

¿Tiene preocupaciones sobre su hijo?
Abajo le brindamos señales de alarma o señales de aviso y síntomas las cuales fueron reportadas por familias con hijos que recibieron un diagnóstico genético. El 89% de las señales de alarma notificadas se notaron antes de los 4 años de edad.

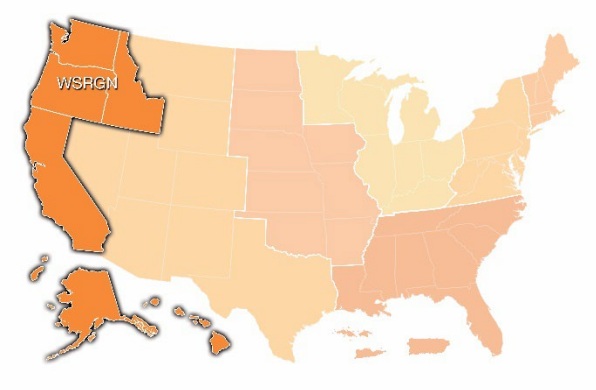
| | | |
|----------------------------------|--|---|
| Retraso del desarrollo | <ul style="list-style-type: none"> Retraso físico/motor (no se da vueltas, no gatea ni camina) Retraso del habla (no balbucea ni responde a su nombre) Adaptable (coordinación de manos y dedos) | <ul style="list-style-type: none"> Cognitivo (no puede o no tiene interés en jugar) Social/emocional (dificultad para interactuar con los demás, no sonríe) Pérdida de logros del desarrollo (regresión) |
| Características físicas | <ul style="list-style-type: none"> Dedos adicionales en los pies o manos Tamaño de la cabeza grande/pequeño (macrocefalia/microcefalia) Estatura baja/alta | <ul style="list-style-type: none"> Paladar hendido Diferentes rasgos faciales (mentón pequeño, frente ancha) Dislocación frecuente de las articulaciones (displasia de la cadera) Deformidades de la columna vertebral (escoliosis) |
| Problemas de alimentación | <ul style="list-style-type: none"> Dificultad para pasar los alimentos Problemas con la lactancia Mal agarre del pecho Dependiente de la sonda de alimentación | <ul style="list-style-type: none"> Nunca se siente saciando Falta de apetito Vómitos Se atraganta con la comida |
| Comportamiento | <ul style="list-style-type: none"> Desorden del Espectro Autista (ASD) Movimientos repetitivos Está constantemente molesto o llorando Falta de contacto visual | <ul style="list-style-type: none"> Dificultad en la escuela o en entornos sociales TDAH/Comportamiento impulsivo o hiperactivo Se distrae fácilmente Llora o tiene un tono de voz agudo, como un grito |
| Falta de crecimiento | <ul style="list-style-type: none"> Crecimiento lento Aumento de peso lento Falta de desarrollo | <ul style="list-style-type: none"> Se fatiga rápidamente cuando está activo El peso o la tasa de aumento de peso es mucho más bajo que el de otros niños |
| Fuerza y tono muscular | <ul style="list-style-type: none"> Tono muscular flácido o bajo (hipotonía) Tono muscular rígido o alto (hipertonía) El bebé no intenta darse la vuelta ni mantiene la cabeza erguida al estar boca abajo | <ul style="list-style-type: none"> Debilidad muscular Tiene el cuerpo flácido Incapacidad de levantar o controlar la cabeza (deja caer la cabeza hacia atrás) |
| Otras Señales | <ul style="list-style-type: none"> Convulsiones Falta de sueño Fatiga Letargo Preocupaciones auditivas/visuales | <ul style="list-style-type: none"> Problemas inmunológicos Dolores de cabeza/migrañas Preocupaciones neurológicas Preocupaciones pulmonares / cardíacas Problemas del sistema digestivo Moretones |

Si su hijo muestra alguna 'señal de alarma' aquí mencionada, hable con el pediatra o médico de atención primaria de su hijo. Para obtener más recursos y ayuda para tener esa conversación, visite:
www.mountainstatesgenetics.org/redflag

Este proyecto está financiado por la Administración de Recursos y Servicios de Salud (HRS) del Departamento de Salud y Servicios Humanos (HHS) de los EE. UU. bajo el número de subvención 5A79AC30776, por \$600,000. Esta información o contenido pertenece al autor y no deben ser considerados una opinión oficial o política de la HRS, HHS ni del gobierno de los EE. UU. ni se debe asumir ningún apoyo por parte de ellos.

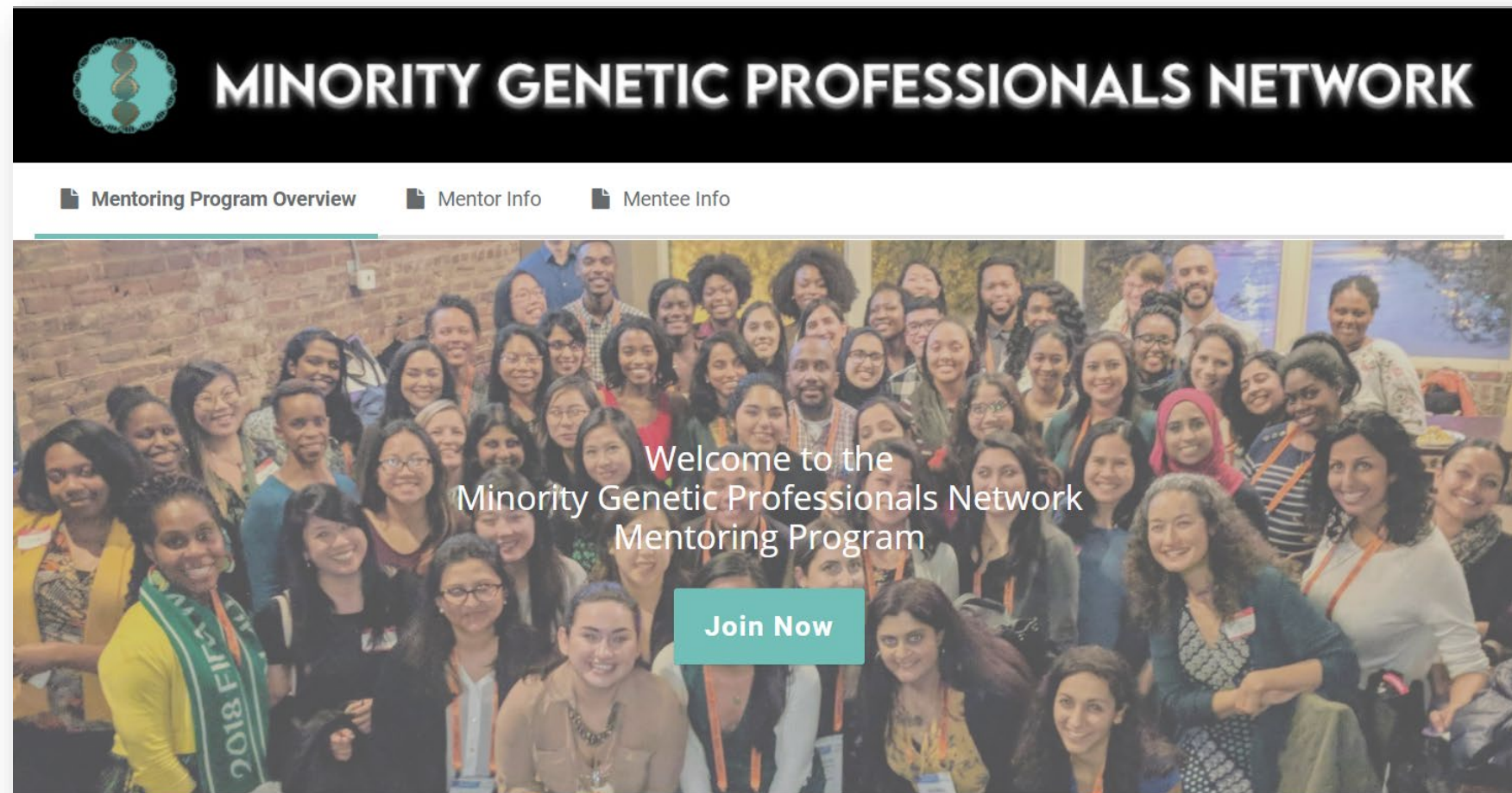
Red Flags 4 Genetics (available in English and Spanish) share family identified symptoms/signs that could be an indication of a genetic condition.

<https://www.mountainstatesgenetics.org/msrgn-launches-spanish-red-flags-4-genetics-handout-for-families-and-providers/>



Minority Genetics Professionals Network

<https://minoritygenetics.org/>



A network of genetics professionals from diverse backgrounds to connect and support each other and increase the diversity of genetics professionals.

Select NCC Activities-

Genetics and Genomics Education

ACT Sheets and Algorithms



[https://acmg.net/
act](https://acmg.net/act)

Clinical decision support tool for non-genetics providers
for the following conditions categories:

- Newborn Screening
- Secondary Findings
- Non-Invasive Prenatal Screening
- Transition
- Carrier

New Updates

ACT Sheets

- 14 Updated ACT Sheets
- 11 Updated Algorithms
- 3 New Algorithms

Animated CME Video to accompany
ACT Sheets:

- SMA and X-ALD available now



Healthcare Interpreter Training



<https://nccrcg.org/interpreting-for-genetics/>

NCC works with Cindy Roat and the Healthcare Interpreter Network to develop three healthcare interpreter modules: prenatal, pediatric, and Autism Spectrum Disorder. All three curricula are available on the NCC website.

New Updates

Trainings have been held in each RGN this year with 140 interpreters trained. The trainings are being expanded to include a cancer genetics curriculum and five new glossaries are being added for the existing curriculums.



Medical Necessity Webinar Series

May 20 at 1 PM ET and June 29 at 2 PM ET



Genetics Workshop for PAs

Next week and available online through AAPA



Evidence-Based Guideline Webinar Series

Starting in June

Resource Repository



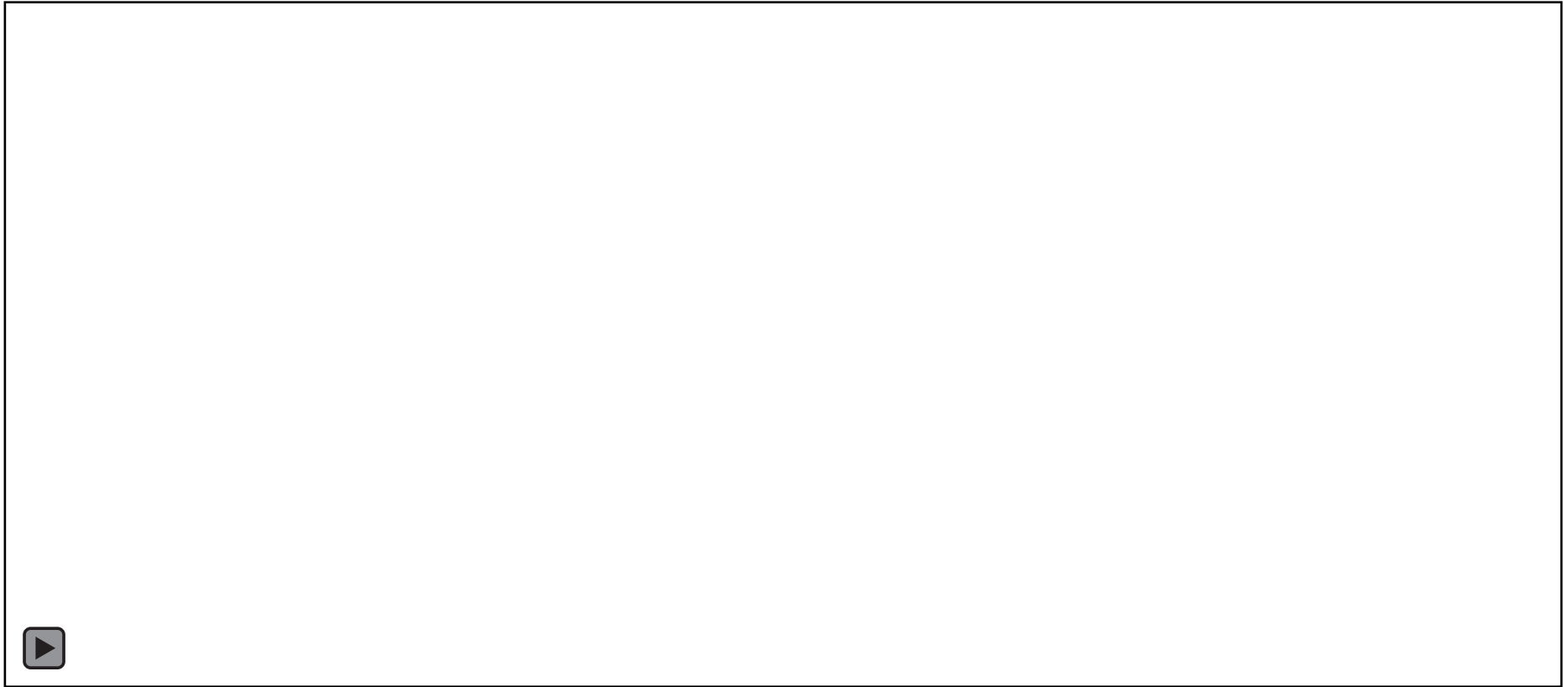
[nccrcg.org/
resources](https://nccrcg.org/resources)



New Policy Website



geneticspolicy.
nccrcg.org



Policy Resources



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

May 23-27, 2022



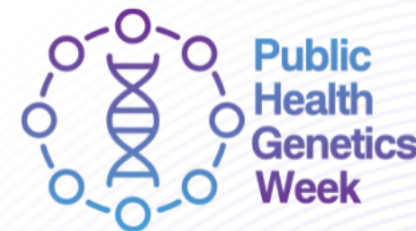
Public health genetics week seeks to raise awareness, and to celebrate, the field of public health genetics. Held during the last week of May, PHGW engages a variety of audiences to highlight the activities of public health genetics.

phgw.org

#PHGW
#PublicHealthGenetics

2022 CALENDAR

Eastern Daylight Saving Time (EDT)



Monday- May 23

What is Public Health Genetics?

Webpage/ Fact Sheet([link](#))

For professionals

1 PM: MGN-Precision Public Health ECHO Series- Family Health History: A Critical Component of Precision Public Health ([here](#))

3 PM: The Role of Education in Public Health Genetics ([here](#))

For students

6 PM: Reddit AMA with Public Health Genetics Students ([here](#))

Tuesday- May 24

Who is Involved in Public Health Genetics?

Webpage/ Fact Sheet([link](#))

For all partners in public health genetics

9 AM: MGN- A Conversation with Public Health Genetics Partners Facebook Live ([here](#))

3 PM: Highlighting the Roles of Public Health Stakeholders: A Twitter Chat ([here](#))

For students

8 PM: A Day in the Life: A Conversation with Pitt Public Health Students about Studying Public Health Genetics ([here](#))

Wednesday-May 25

What are Public Health Genetics Programs?

Webpage/ Fact Sheet([link](#))

For the general public

12 PM: Simons Searchlight- LIVE Q&A: Ask a Simons Searchlight Genetic Counselor ([here](#))

4:30 PM: Facebook Live: The Family Perspective on Family Health History ([here](#))

For professionals

1 PM: MGN-Precision Public Health ECHO Series- Risk-Based Genetic Screening ([here](#))

Thursday- May 26

Public Health Screening

Webpage/ Fact Sheet([link](#))

For the general public

2 PM: Baby's First Test-Updates in Newborn Screening Policy, Technology, and Research: Where are We Now? ([here](#))

For professionals

11 AM: Applied Research in Public Health Genomics at the Centers for Disease Control and Prevention ([here](#))

1 PM: MGN- Precision Public Health ECHO Series- Population-Based Genetic Screening ([here](#))

Friday- May 27

Public Health Genetics Resources

Webpage/ Fact Sheet([link](#))

For all partners in public health genetics

2 PM: Public Health Genetics Resources: A Twitter Chat ([here](#))

For professionals

1 PM: The Role of Policy Education in Public Health Genetics: An Overview of the Genetics Policy Hub ([here](#))

Our [toolkit](#) includes:

- Daily social media images
- PHGW colors and logos
- Email signature banners
- Social media banners
- GIFs
- Virtual meeting backgrounds

Available PHGW Resources

In addition to the events, we have plenty of fun, interactive activities:

- Book Club
- [Coloring pages](#)
- Escape Room
- Puzzles

PHGW Activities



Contact Us



Maximilian Muenke, MD
Program Director
mmuenke@nccrcg.org



Megan Lyon, MPH
Associate Project Director
mlyon@nccrcg.org



Molly Caisse
Project Coordinator
mcaisse@nccrcg.org



Annie Li
Project Assistant
ali@nccrcg.org



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