

Cultivating Connections:
Utilizing NYMAC resources
and joining forces with
local collaborators in your
state/district/territory

Cultivar conexiones:
cómo usar los recursos de
NYMAC y unir fuerzas con
colaboradores locales en tu
estado/distrito/territorio

Cheylla Clark, MPH, MS, CGC

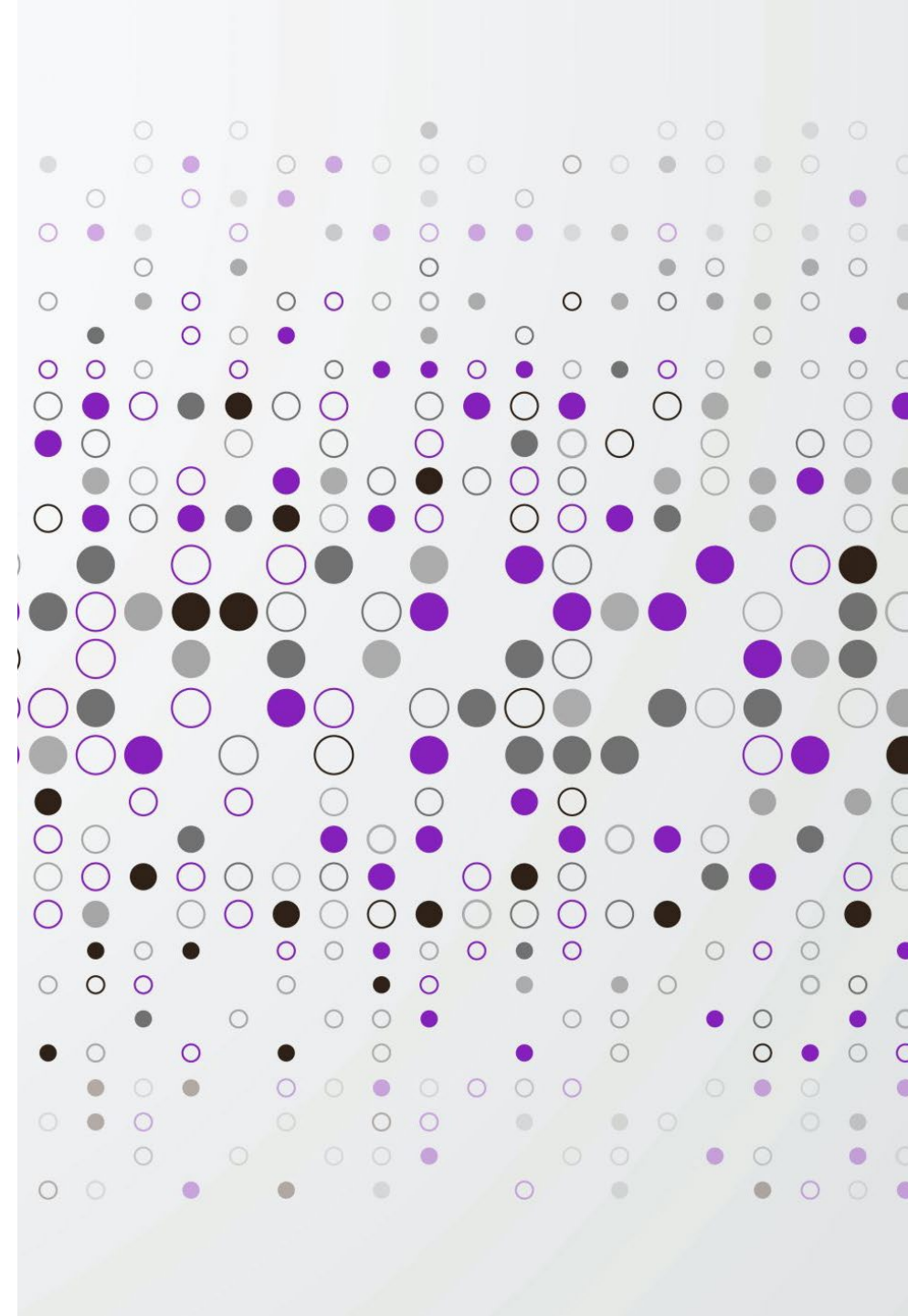
Enrique Lopez, MS, CGC

Radhika Sawh, MS, CGC

April 18, 2024



NYMAC
regional genetics network



Financial Disclosures

Cheyly Clark, MPH, MS,
CGC and Enrique Lopez,
MS, CGC

Have No Relevant
Financial Disclosures.

Divulgaciones financieras

Cheyly Clark, MPH,
MS, CGC y Enrique
Lopez, MS, CGC

No tener información
financiera relevante.

Financial Disclosure

Radhika Sawh, MS, CGC

Discloses the following relevant relationships with ineligible companies. Any potential interests have been mitigated:

Consultant/Honorarium Bristol-Myers Squibb

Consultant/Honorarium Vertex Pharmaceuticals

Divulgacione financieras

Radhika Sawh, MS, CGC

Divulga las siguientes relaciones relevantes con empresas no elegibles. Se han mitigado los posibles intereses:

Consultor/Honorarios Bristol-Myers Squibb

Consultor/Honorarios Vertex Pharmaceuticals

TODAY'S SPEAKERS

LOS ORADORES DE HOY

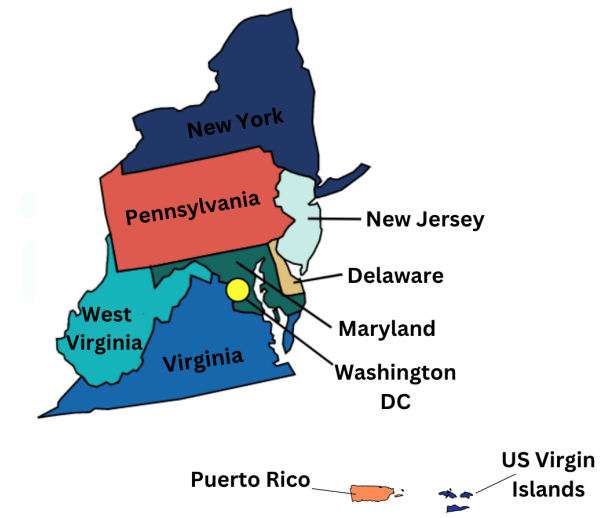


NYMAC TEAMS

- Individual teams were created for each of our 10 jurisdictions
- The goals of each team is to
 - assess the needs and barriers specific to that jurisdiction
 - implement NYMAC funded projects to improve access to genetic services

Equipos NYMAC

- Se crearon equipos individuales para cada una de nuestras 10 jurisdicciones
- Objetivos de cada equipo:
 - Evaluar las necesidades y barreras específicas de esa jurisdicción.
 - Implementar proyectos financiados por NYMAC para mejorar el acceso a servicios genéticos.



POLL/ENCUESTA



What NYMAC region are you joining us from?
¿A qué región de NYMAC perteneces?



NEW YORK TEAM
Equipo de Nueva York



VAGELOS COLLEGE OF
PHYSICIANS AND SURGEONS



NEW YORK

IS AN APPOINTMENT WITH A GENETICS PROVIDER RIGHT FOR YOUR FAMILY?

Sometimes health challenges can be caused by changes in our genes. Genetics providers help families learn whether genetic changes may explain the health conditions in their family and how the family can be best cared for.

It can be helpful to talk to a genetics provider if you are concerned about...

- The way your child speaks, moves, or learns
- The way your child is growing, or difference in the way their body looks or works
- The cause of your child's medical issues such as autism, hearing or vision loss, heart defects or digestive issues
- Your child having multiple unexplained medical issues

OR

- If you or your partner have been told you have a higher chance to have a child with a health challenge
- If you have a family member with a genetic condition or a test result that suggests they may have a genetic condition
- If you wonder if your family's medical issues could have a genetic explanation and/or mean that other family members are at increased risk for health challenges

Scan the QR code or visit our website to learn more about common questions such as:

- How to learn more about how your child's development compares to other children.
- Where to find support
- How to find a genetics provider
- How to learn about insurance coverage
- How to best care for your child as they get older.

<https://nymagenetics.org/ny>

NYMAC regional genetics network

The New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC) aims to make it easier for families to connect to the genetic services and information they need.

It can be helpful to talk to a genetics provider if you are concerned about...

- The way your child speaks, moves or learns
- The way your child is growing, or differences in the way their body looks or works
- The cause of your child's medical issues such as autism, hearing or vision loss, heart defects or digestive issues
- If you or your partner have been told you have a higher chance to have a child with a health challenge
- If you have a family member with a genetic condition or a test result that suggests they may have a genetic condition
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- How to find a genetics provider
- How to learn about insurance coverage
- How to best care for your child as they get older

Is an appointment with a Genetics Provider right for your family?

Sometimes, health challenges can be caused by changes in our genes. Genetics providers help families learn whether genetic changes may explain the health conditions in their family and how the family can be best care for.

NYMAC regional genetics network

<https://nymagenetics.org/marilyn/>

We can help!

New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC) aims to make it easier for families to connect to the genetic services and information they need.

Barrier

Public awareness about when to seek a referral to genetics

Project

Designed an infographic and pocket card focusing on appropriate genetic referrals

Next Steps

Community Outreach Committee of the NYS Genetics Task Force will monitor access issues and continue outreach efforts

Barrera

Concientización pública sobre cuándo buscar una derivación a genética

Proyecto

Se diseñó una infografía y una tarjeta de bolsillo centrada en las referencias genéticas apropiadas.

Próximos pasos

El Comité de Extensión Comunitaria del grupo de trabajo sobre genética del estado de Nueva York controlará los problemas de acceso y mantendrá los servicios de extensión.





Advocates for Justice and Education, Inc.
 The Parent Training and Information Center for the District of Columbia



Children's National®



DC TEAM
Equipo de DC



**MedStar Washington
 Hospital Center**



**Mary's
 Center**

DC Families Share Their Genetic Journey



Participate in a virtual discussion to help families in the DC community explore and gain better access to genetic services.

Share your experience with genetic services and counseling with another family via Zoom. Your conversation will be professionally recorded and edited and will be shared on social media and projects websites. For additional questions contact LaJoy Johnson-Law-lajoy.johnson-law@aje-dc.org.

Learn More Here: <https://NYMACGenetics.org/dc/>

SIGN UP AT: [HTTPS://TINYURL.COM/GENETICSENGLISH](https://tinyurl.com/geneticsenglish)

FAMILIES THAT PARTICIPATE WILL ALSO RECEIVE COMPENSATION OF \$150 GIFT CARD.

THIS WORK 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 \$200,000 WITH A PRESENT FUNDING WITH HHS GOVERNMENTAL AWARD. 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.HHS.GOV

DC

Barrier

Families not understanding the value and relevance of genetics AND distrust in genetics professionals

Project

Created "My DC Genetics Journey" videos featuring local families sharing their experiences with genetics

Next Steps

Outreach Committee of the Maryland and DC Society of Genetic Counselors will support providers

Barrera

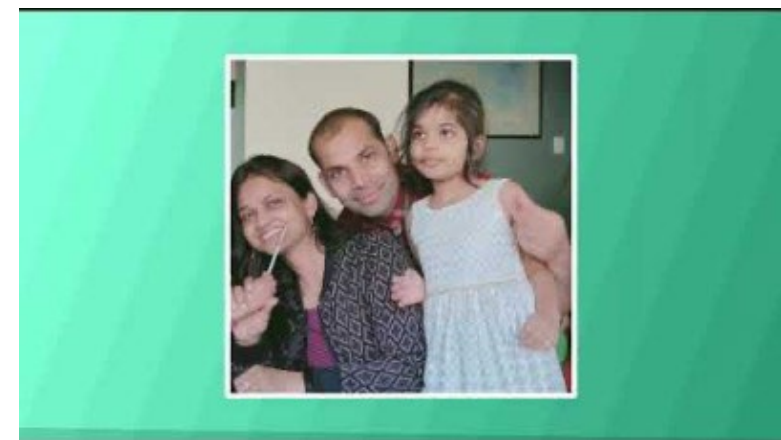
Las familias no comprenden el valor y la relevancia de la genética Y desconfían de los profesionales que se dedican a la genética.

Proyecto

Se crearon videos denominados "My DC Genetics Journey", que muestran familias locales que comparten sus experiencias con la genética.

Próximos pasos

El Comité de Extensión de la MDCGC (Sociedad de Asesores Genéticos de Maryland y DC) brindará ayuda a los proveedores.





VDH VIRGINIA
DEPARTMENT
OF HEALTH



VVCU



VIRGINIA TEAM
Equipo de Virginia

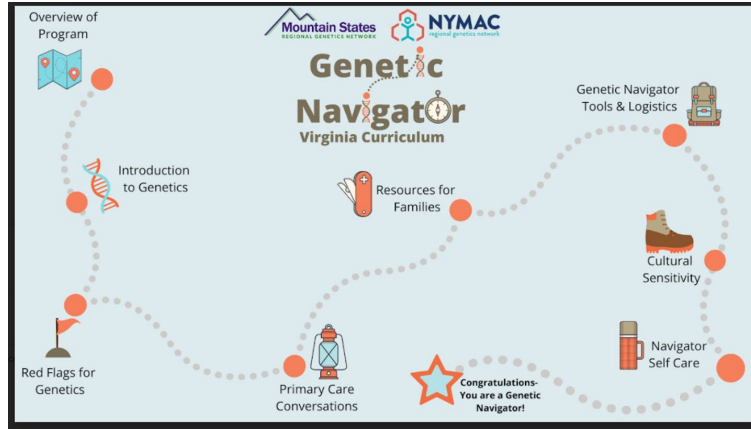


Pediatric Specialists
of Virginia



**Children's
Hospital
of The King's
Daughters**

VIRGINIA



Barrera

Necesidad de educación y apoyo a las familias que requieren servicios genéticos

Proyecto

Se elaboró un complemento de capacitación de "Genetic Navigator" (navegador genético) para voluntarios y empleados de CFI (F2F local) que tienen experiencia genética previa.

Próximos pasos

CFI continuará con el programa VA Genetic Navigator.

Promover el uso del programa GN por parte de proveedores de servicios genéticos y otros.

Barrier

Need for education and support families who require genetics

Project

Developed a "Genetic Navigator" training add-on for volunteers and employees at CFI (local F2F) with prior genetic experience

Next Steps

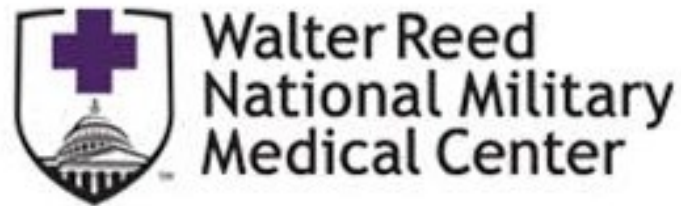
CFI will continue the VA Genetic Navigator program

Promote use of GN program by genetics and non-genetics providers





MARYLAND TEAM
Equipo de Maryland



MARYLAND

Barrier

Need for education of providers and families about appropriate referrals to genetics

Project

Created infographics focusing on pediatric, cancer and general genetics referrals

Next Steps

MDCGC will collaborate with the Parents Place of Maryland to provide support to families

MDCGC will facilitate genetic referrals for Maryland Rural Health Association

Barrera

Necesidad de educar a los proveedores y a las familias sobre las derivaciones apropiadas a genética

Proyecto

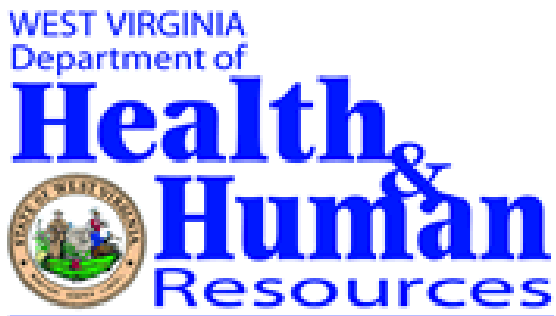
Se crearon infografías centradas en referencias pediátricas, oncológicas y de genética general.

Próximos pasos

MDCGC colaborará con Parents Place of Maryland para ayudar a las familias.

MDCGC facilitará referencias genéticas para la Asociación de Salud Rural de Maryland.





WEST VIRGINIA TEAM
EQUIPO DE VIRGINIA OCCIDENTAL



WEST VIRGINIA

Barrier

Lack of education of providers about the value of genetic services

Project

Support efforts to build a genetics infrastructure at WVU

Fund genetics education for providers

Genetics focused outreach to providers

Next Steps

Support efforts to pass Licensure bill for genetic counselors

Continue to expand genetic services in WV

Barrera

Falta de educación de los proveedores sobre el valor de los servicios genéticos

Proyecto

Apoyar las medidas para construir una infraestructura genética en WVU.

Financiar educación genética para proveedores.

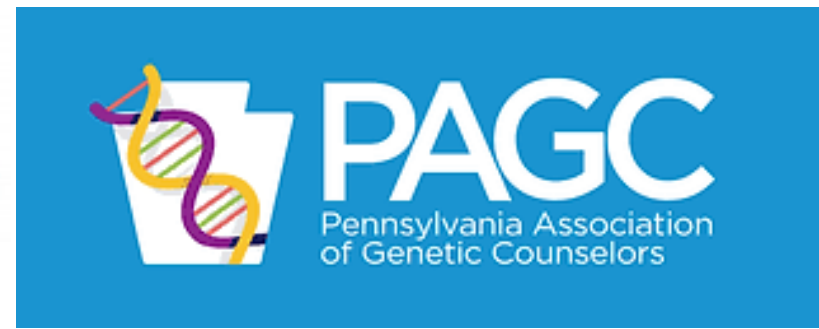
Ofrecer programas de extensión centrados en la genética para proveedores.

Próximos pasos

Apoyar los esfuerzos para aprobar un proyecto de ley de licencias para asesores genéticos.

Seguir ampliando los servicios genéticos en Virginia Occidental.





PENNSYLVANIA TEAM

EQUIPO DE PENSILVANIA



Pennsylvania Chapter

INCORPORATED IN PENNSYLVANIA

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®



Geisinger



PENNSYLVANIA

Barrier

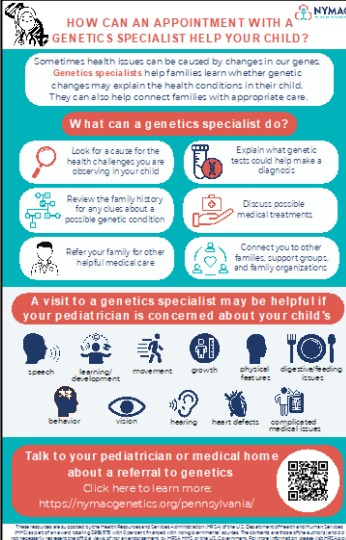
Need to educate providers and families about genetic services and appropriate referrals

Project

Created separate family and provider infographics on genetic services

Next Steps

Outreach by Genetic Services Committee of the Pennsylvania Association of Genetic Counselors to increase awareness



Barrera

Necesidad de educar a los proveedores y las familias sobre los servicios genéticos y las derivaciones adecuadas

Proyecto

Se crearon infografías separadas para familias y proveedores sobre servicios genéticos.

Próximos pasos

Divulgación del Comité de Servicios Genéticos de la PAGC (Asociación de Asesores Genéticos de Pensilvania) para sensibilizar al público.





New Jersey Chapter

INCORPORATED IN NEW JERSEY

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®



NEW JERSEY TEAM
EQUIPO DE NUEVA JERSEY



NEW JERSEY

Barrier

Need to educate providers and families about appropriate referrals to genetics

Project

Developed a Genetics training for NJ Community Health Workers Institute

Next Steps

Community Outreach Committee of the Human Genetics Association of NJ will support genetic trainings by the CHW Institute

Barrera

Necesidad de educar a los proveedores y a las familias sobre las derivaciones apropiadas a genética

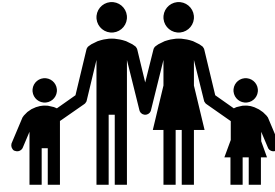
Proyecto

Se diseñó una capacitación en genética para el Instituto de Trabajadores de Salud Comunitarios de Nueva Jersey.

Próximos pasos

El Comité de Extensión Comunitaria de la HGANJ (Asociación de Genética Humana de Nueva Jersey) apoyará las capacitaciones sobre genética del Instituto CHW.





DELAWARE TEAM
EQUIPO DE DELAWARE



Member of the
CCRM Fertility Network



DELAWARE



Barrier

Health disparities/
underserved communities

Project

Created a family infographic on genetic services and a flyer on sickle cell trait

Next Steps

Delaware GCs will support efforts to increase awareness of genetic services by local organizations

Barrera

Disparidades de salud/comunidades desatendidas

Proyecto

Se creó una infografía familiar sobre servicios genéticos y un folleto sobre el rasgo de la célula falciforme.

Próximos pasos

Los asesores genéticos de Delaware apoyarán las iniciativas para educar a las organizaciones locales sobre los servicios genéticos.



PUERTO RICO FAMILY-TO-FAMILY CENTER



UPR



Puerto Rico



Tamdiu Discendum Est. Quamdiu Vivas



Puerto Rico

Barrier

Lack of provider education about genetic services on the island

Lack of genetics providers

Project

Provide workshops for both families and providers on the value of genetic services

Increase access to genetics counseling services to alleviate burden on existing providers

Next Steps

Work on genetic education videos in Spanish for providers

Support the genetic counseling profession to be recognized on the island



Barrera

Falta de educación de los proveedores sobre los servicios genéticos en la isla

Falta de proveedores de servicios genéticos

Proyecto

Dictar talleres para familias y proveedores sobre el valor de los servicios genéticos.

Aumentar el acceso a los servicios de asesoramiento genético para aliviar la carga de los proveedores disponibles.

Próximos pasos

Crear videos de educación genética en español para proveedores.

Promover que se reconozca la profesión de asesoramiento genético en Puerto Rico.



US Virgin Islands
Islas Vírgenes de Estados
Unidos



University of the Virgin Islands

**VIRGIN ISLANDS SICKLE CELL
PARENT SUPPORT GROUP**

(340) 277-3579 • (340) 778-3668
(340) 772-2157 • (340) 778-0057

P.O. Box 4389 Kingshill
V.I. 00851 - 4389

KEEP US SMILING • WITH YOUR SUPPORT

Germaine Powell

U.S. Virgin Islands

Barrier

Lack of providers to provide genetic services

Lack of expansive genetics education

Project

Provide family and provider training workshops on the topic of genetics

Recruit a geneticist, create genetics education tools, and help to secure funding for MCH pediatrician and newborn screening tracking system

Next Steps

Set up genetics clinic

Build out Newborn Screening tracking system

Continue genetics education through shared resources

Barrera

Falta de proveedores para brindar servicios genéticos

Falta de educación genética amplia

Proyecto

Brindar talleres de capacitación para familias y proveedores sobre genética.

Se contrató a un genetista; se crearon herramientas de educación genética y se obtuvo financiación para el pediatra del MCH y el sistema de seguimiento de exámenes de detección de recién nacidos.

Próximos pasos

Montar una clínica de genética.

Se elaboró un sistema de seguimiento de detección de recién nacidos.

Continuar la educación genética a través de recursos compartidos.



A hand-drawn diagram on a whiteboard background. On the left, three human profiles are shown in profile, facing right. Each head contains several interlocking gears of different sizes. Above each head is a small, simple line drawing of a lit lightbulb. Curved arrows connect the top of each head to the top of the next head to its right. A larger arrow points from the top of the third head to the top of a large, detailed lightbulb on the right. This large lightbulb has a glowing yellow filament and several short, radiating lines around it, indicating it is lit. A hand is visible at the bottom right, holding a yellow marker and pointing towards the large lightbulb.

BREAKOUT ROOMS:

Meet collaborators from your area and share your ideas

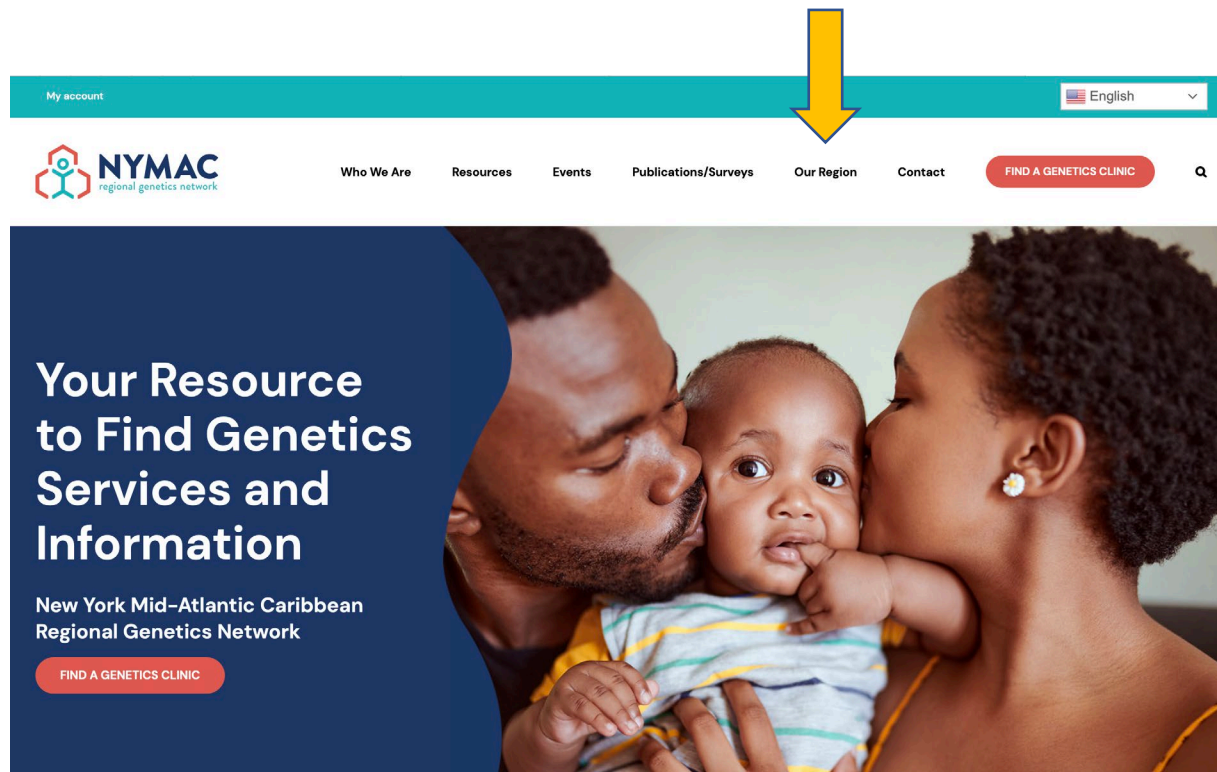
SALAS DE TRABAJO EN GRUPO:

Conoce a colaboradores de tu zona y comparte tus ideas

How can you
foresee
continuing
these efforts?

¿Cómo puedes
prever
mantener estas
iniciativas?





Stay up to date on progress in your region through the individual teams' webpages on the NYMAC Website:

<https://nymacgenetics.org>

Mantente actualizado sobre el progreso en tu región a través de las páginas web de los equipos individuales en el sitio web de NYMAC:

<https://nymacgenetics.org>

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WANT TO
CONTINUE THE
CONVERSATION?

¿QUIERES SEGUIR
CONVERSANDO?

