



Westchester Institute
for Human Development

<https://www.wihd.org>

Welcome!

Community Support Network Transition Institute 2022



NYMAC
regional genetics network



CONSIDERATIONS AND SUPPORT FOR TRANSITION PLANNING FOR FAMILIES WITH A GENETIC CONDITION

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We have no conflicts of interest to disclose

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INTRODUCTIONS

TRANSITION AND GENETICS

Health care transition, or HCT, is the process of getting ready for health care as an adult. During childhood, your parents and caregivers usually help with your health and health care needs—they call for appointments, fill out forms, and keep track of medications. As you get older, managing those needs becomes your own responsibility. Achieving this independence requires an organized transition process to gain independent health care skills, prepare for an adult model of care, and transfer to new clinicians.

<https://www.gottransition.org/youth-and-young-adults/>

Transition is an ongoing process that does not end with transfer of care. The goal of transition of adolescents with chronic medical conditions is to provide uninterrupted, comprehensive, culturally sensitive, coordinated, and developmentally appropriate healthcare. The transition team includes at least the patient and family, and the pediatric, adult PCP, and specialty care providers.



PARENT TO PARENT OF NYS

#TEXT4
Caregivers

- Regional offices throughout NYS.
- Network of over 1,200 trained volunteer Support Parents is the foundation of the parent to parent program.
- Additional networking capabilities with parent to parent programs throughout the United States.
- Well maintained website with announcements, news and events.
- Funded by NYS Office For People with Developmental Disabilities (OPWDD) and HRSA through MCHB.



www.parenttoparentofnys.org





***My personal link between
Parent to Parent of NYS
and NYMAC***

***Introducing the
Perry Fab4!***

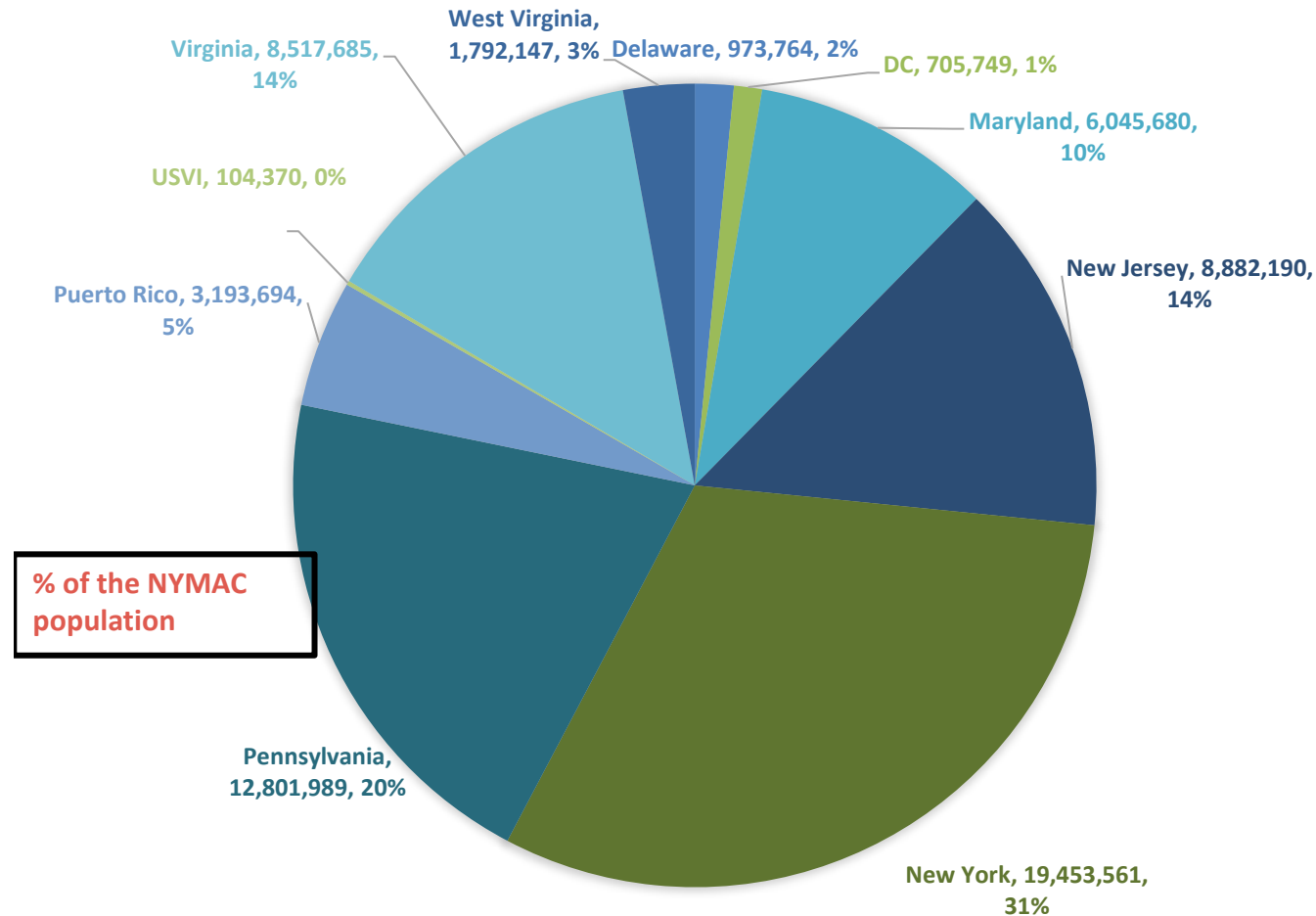
***(I have learned a lot about
transition!)***



NYMAC BACKGROUND

NYMAC (New York-Mid-Atlantic-Caribbean Regional Genetics Network)

- Delaware
- The District of Columbia
- Maryland
- New Jersey
- New York
- Pennsylvania
- Puerto Rico
- Virginia
- West Virginia,
- The US Virgin Islands



Who We Are
NYMAC
NYMAC is one of seven federally funded regional genetics networks in the U.S. and Territories, committed to improving access to genetics services.

What We Do

Access to Care

Individuals from our region with genetic disease and their families, advocates, healthcare professionals and public health professionals collaborate to ensure that individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise.



Where We Are
Our Region
The NYMAC region includes Delaware, District of Columbia, Maryland, New Jersey, New York, Pennsylvania, Virginia, West Virginia, Puerto Rico and the U.S. Virgin Islands.



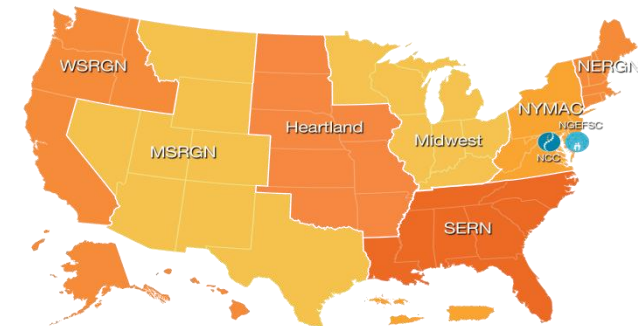
WHO HAS USED NYMAC RESOURCES?



NYMAC, NCC, and HRSA

- There are seven Regional Genetics Networks (RGNs) supported by federal grant funding from The Health Resources and Services Administration (HRSA) to ensure that underserved individuals with genetic conditions and their families have access to quality care.
- The seven RGNs, supported by the **National Coordinating Center** (“NCC” housed at ACMG) and **The National Genetics Education and Family Support Center**, work to meet the unique needs of their respective regional areas. <https://nccrcg.org/rgn/>
- The National Genetics Education and Family Support Center (Family Center) **provides tools and resources to support family engagement in genetic services** through a partnership between Genetic Alliance, SPAN Parent Advocacy Network, and Parent to Parent USA supported by the a federal HRSA grant

WHO HAS WORKED WITH THE FAMILY CENTER?



National Genetics
Education and
Family Support Center

Contact: Molly Martzke mmartzke@expectinghealth.org

WHAT DOES NYMAC DO?

Who Does NYMAC Collaborate With?

*Family organizations
People with genetic conditions
Cultural organizations
Professional societies
Genetics Clinics and Service Providers
Pediatricians, family doctors, specialists, nurses
Newborn Screening Programs
MCH, Title V, CYSHCN, EDHI, LEND,
Support Groups
Early intervention
Perinatal networks
And many more*



Improving the genetics delivery system through collaboration with diverse stakeholders



Telemedicine projects to make genetics appointments easier for families



Education about genetics to families and professionals

To achieve

ACCESS to quality genetics services for people with genetic conditions and their families

WHY GENETICS?









Some health challenges and disabilities can be caused by changes in our genes.

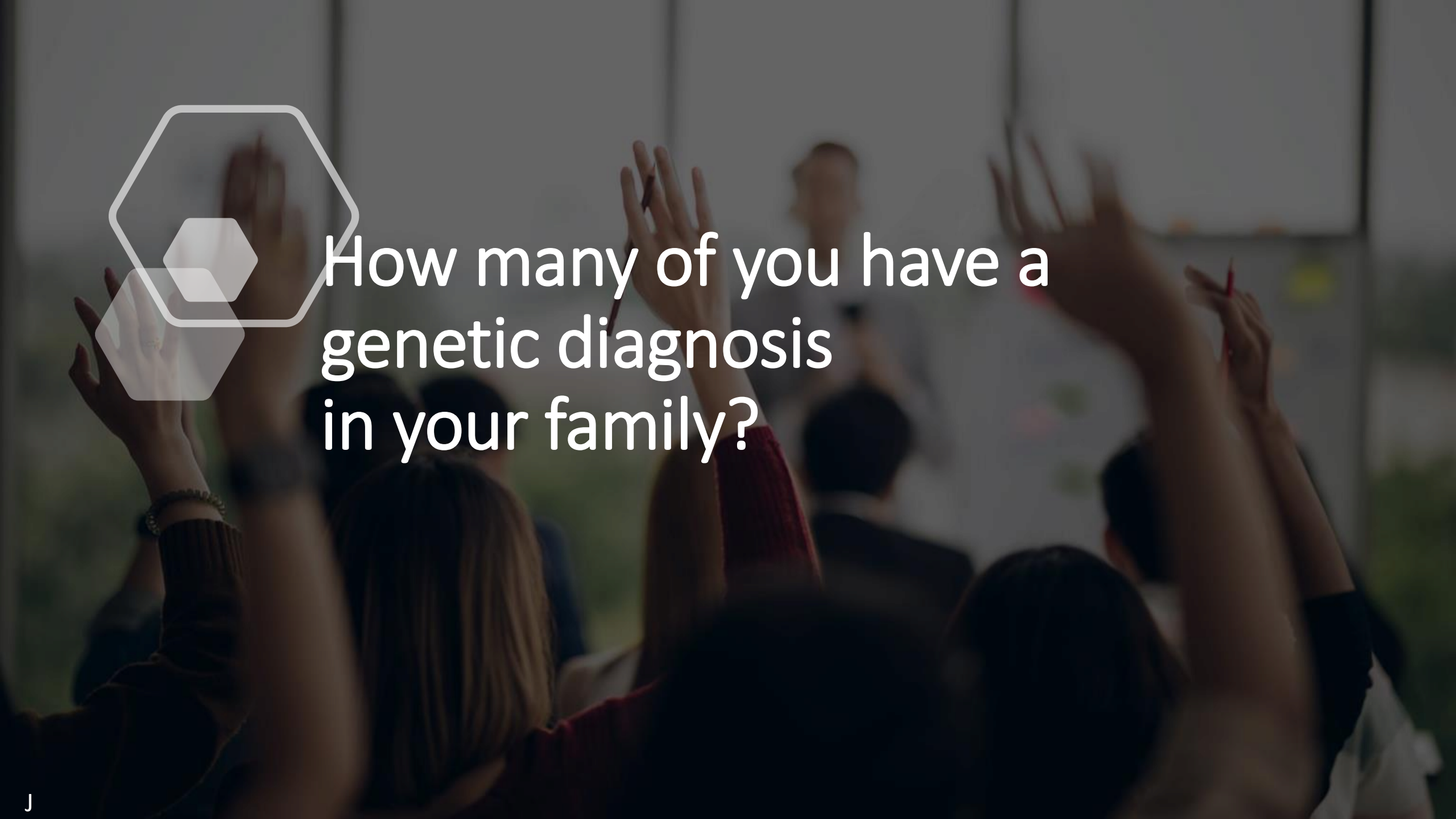
Genetics providers help families learn whether genetic changes may explain the health conditions in their family and how the family can be best cared for.

What Types of Conditions Might be Related to Genetics?

- Autism Spectrum
- Sickle Cell Disease
- Developmental Delay
- Intellectual Disability
- Deafness Hard of Hearing
- Blindness or Low Vision
- Albinism (e.g. HPS)
- Congenital Anomalies
- Cystic Fibrosis
- Down Syndrome
- Cancer
- Heart Disease
- Alzheimer's Disease

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*
-  *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*
-  *Your child having multiple unexplained issues*



How many of you have a
genetic diagnosis
in your family?

TRANSITION CONSIDERATIONS FOR THOSE WITH A GENETIC DIAGNOSIS

- If your child got a genetics diagnosis many years ago. It will be useful to follow up with genetics to get updated information as your child plans to transition out of pediatric care
- Following up with all of the specialists while planning for transition can be very helpful
 - Always take your family history and your genetics history with you to other doctors
 - A thoughtful and coordinated team approach with various providers is key to successful transitions
- Help prepare adolescents to be knowledgeable about their genetic condition and advocate for themselves
 - E.g., young adult going to the ER or health clinic alone for the first time, filling out paperwork
 - Again, a coordinated care team can be key
 - Transition to adult specialists before the need to see one becomes urgent
- Finding a genetics provider for an adult can be even harder than a pediatric due to fewer providers. If you have a pediatric geneticist and will need adult care, ask for transition of care options.

ACMG TRANSITION ACT SHEETS

https://www.acmg.net/ACMG/Medical-Genetics-Practice-Resources/ACT_Sheets_and_Algorithms.aspx

The ACMG ACT Sheets are a resource for information on genetic conditions developed by the American College of Medical Genetics and Genomics and the National Coordinating Center for the Regional Genetics Networks ([NCC](#)). ACT Sheets are excellent refreshers on the conditions, diagnoses, and next steps for patients.

Transition to Adult Health Care ACT Sheet

Transition is an ongoing process that does not end with transfer of care. The goal of transition of adolescents with chronic medical conditions is to provide uninterrupted, comprehensive, culturally sensitive, coordinated, and developmentally appropriate healthcare. The transition team includes at least the patient and family, and the pediatric, adult PCP, and specialty care providers.

American College of Medical Genetics **ACT**

Transition to Adult Health Care ACT Sheet

Transition is an ongoing process that does not end with transfer of care. The goal of transition of adolescents with chronic medical conditions is to provide uninterrupted, comprehensive, culturally sensitive, coordinated, and developmentally appropriate healthcare. The transition team includes at least the patient and family, and the pediatric, adult PCP, and specialty care providers. For the general pediatric population, refer to the [2011 AAP/AACOG/ACMG Transition Toolkit](#), which includes the recommendation that transition planning begin no later than age 12 and include a patient readiness assessment.

Congenital Hypothyroidism

Condition Description: Congenital hypothyroidism (CH) is predominantly a non-genetic condition identified by newborn screening. In both the primary (generally thyroid agenesis or ectopia) and secondary (posthypopituitarism) forms, there is a lack of adequate thyroid hormone production.

Clinical Considerations: Most individuals with adequately controlled congenital hypothyroidism do not manifest intellectual disability, growth impairment, or delay in bone maturation. Inadequate treatment may result in delayed puberty and impaired fertility. Pregnancies should be considered high risk. Offspring of mothers with untreated low thyroid function during pregnancy (maternal hypothyroidism) may have reduced cognitive function and learning difficulties.

THE TRANSITION TEAM SHOULD TAKE THE FOLLOWING ACTIONS:

- Initiate a dialogue among transition team members and establish an adult medical home.
- Facilitate consistency and coordination of care among multiple health care providers as the patient transitions to independent living (to include college, relocation, employment).
- Consult with an endocrinologist, if appropriate.
- Review the medical record and previous laboratory studies.
- Order laboratory studies, including thyroid function tests - routine TSH and, if indicated, free T₄.
- Develop and implement a comprehensive care plan that includes:
 - Continuation of appropriate thyroid therapy
 - Preconception counseling - discuss potential increase of thyroid hormone dose as soon as a woman knows she is pregnant (maternal hypothyroidism, especially in the first trimester, may be associated with cognitive loss in offspring)
 - Referral of pregnant CH patient for management of potentially high risk pregnancy
- Identify the patient's health care coverage (including insurance) and access to care.
- Assess and address the patient's psychological, behavioral, and social service needs.
- Offer health education and genetic counseling concerning future reproductive decisions.

Additional Information:

- [AAP/AAP/ACP Transition Clinical Report](#)
- [Transition Toolkit](#) (New England Consortium of Metabolic Programs)
- [Got Transition](#)
- [American Association of Clinical Endocrinologists](#)
- [Endocrine Society](#)
- [American Thyroid Association](#)

Referral (local, state, regional and national):

- [Clinical Services](#)
- [Find Genetic Services](#)

LOCAL RESOURCES: Insert State program web site links

State Resource site (insert program information)

Name	<input type="text"/>
URL	<input type="text"/>
Comments	<input type="text"/>

APPENDIX: Resources with Full URL Address

- Additional Information:**
- [AAP/AAP/ACP Transition Clinical Report](#)
 - [http://angphc.aapophth.com/transitionpediatrics/1281/182.pdf](#)
 - [New England Consortium of Metabolic Programs Transition Toolkit](#)
 - [http://newenglandconsortium.org/for-families/transition-toolkit/](#)
 - [Got Transition](#)
 - [http://www.gettransition.org](#)
 - [American Association of Clinical Endocrinologists](#)
 - [https://www.aace.com](#)
 - [Endocrine Society](#)
 - [http://www.endo-society.org/](#)
 - [American Thyroid Association](#)
 - [http://www.thyroid.org/](#)
- Referral (local, state, regional and national):**
- [Clinical Services](#)
 - [http://www.ncbi.nlm.nih.gov/ncbi/GeneticTests/links/0to-GeneticTests](#)
 - [Find Genetic Services](#)
 - [http://www.acmg.net/US/Disorder.aspx](#)

Transition ACT Sheets

Endocrine Disorders

Hemoglobin Disorders

Urea Cycle Disorders

Amino Acidemias

Galactosemias



TRANSITION AND EDUCATION SETTINGS

- Considerations for college or other post secondary program—what does your child qualify for and empower your child to understand the system
- How to inform educators and school staff about a genetic condition and associated needs and accommodations
- See also:
 - <https://nymacgenetics.org/patients-and-families/school-and-support-resources/>
 - <https://nymacgenetics.org/patients-and-families/advocacy-and-support-resources/>

<https://www.negenetics.org/genetic-education-materials-school-success-gemss>



FIND A CLINIC CONTACT US SEARCH NEW ENGLAND REGIONAL GENETICS NETWORK

nergn NEW ENGLAND REGIONAL GENETICS NETWORK

Home About Us GEMSS Families Professionals Resources

Genetic Education Materials for School Success (GEMSS)

gemss

For Families For Health Care Providers For Schools



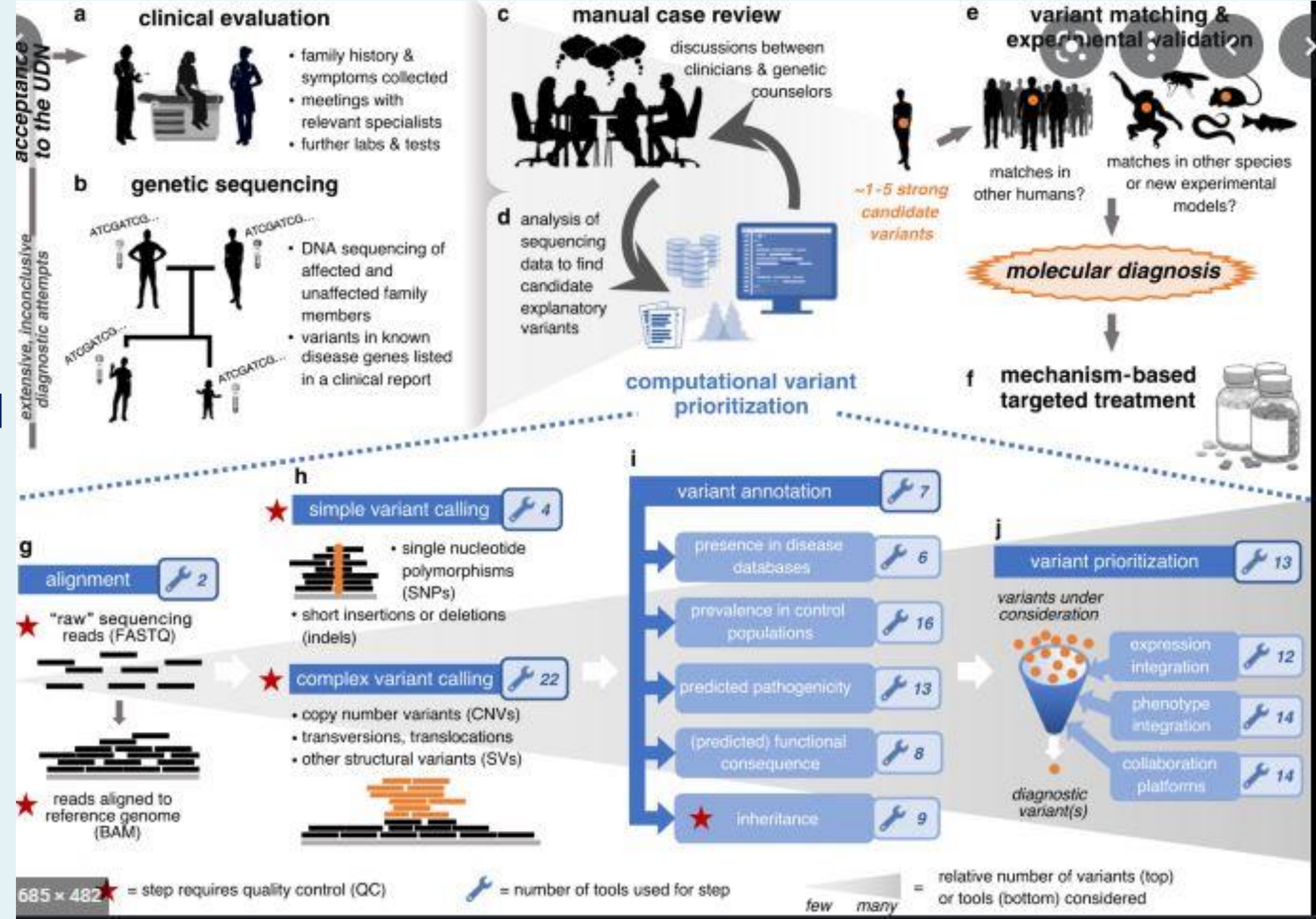
**How many of you
have seen a
genetic specialist
but left with
remaining
questions and
concerns?**

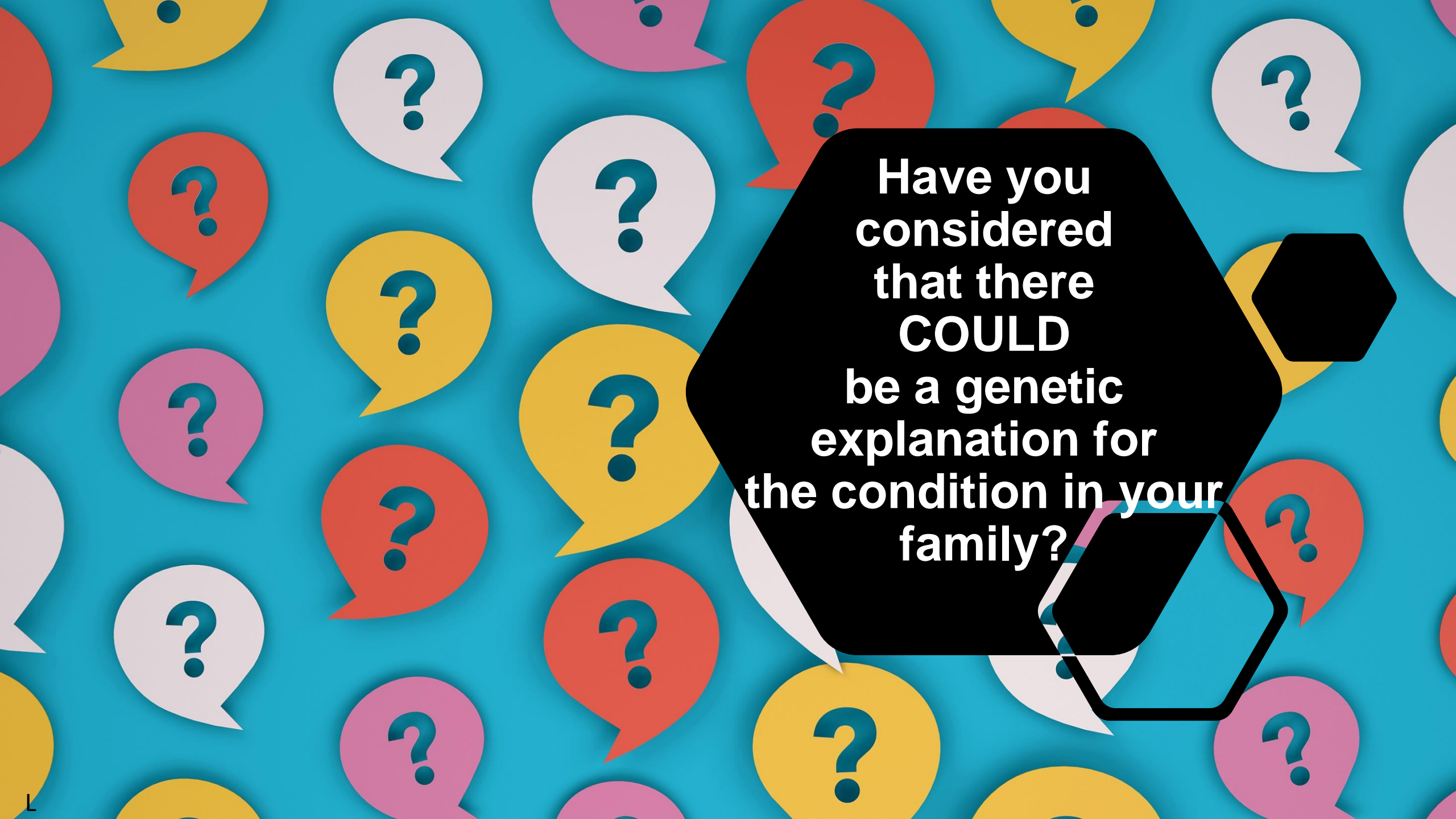
Even if you've seen a geneticist already...

- Often the genetics team will recommend to return to clinic in the future
 - Technology evolves, making new testing and possibly clinical trials (clinicaltrials.gov) or therapies available
 - Signs and symptoms may present later as kids get older and may provide new clues for a diagnosis
 - Family history may change or be clarified
 - New symptoms may need further evaluation and/or another specialist
- Some geneticists have special expertise, In some cases a second opinion may be helpful. Do your research and reach out to geneticists or genetic counselors
- Keep trying!



The Example of the Undiagnosed Disease Network (UDN)



The background is a vibrant blue with a repeating pattern of colorful speech bubbles in shades of yellow, red, pink, and white. Each bubble contains a dark blue question mark. A large, black, irregular hexagonal shape is overlaid on the right side of the image, containing white text.

**Have you
considered
that there
COULD
be a genetic
explanation for
the condition in your
family?**

TRANSITION CONSIDERATIONS FOR THOSE SEEKING A GENETIC DIAGNOSIS

- Always take your family history and your genetics history with you to other doctors
- If you haven't gotten a full diagnosis yet, genetics may be able to identify potential causes that you haven't considered. They may have the key to what is going on and what else to look for.
- Genetics looks at the whole picture, the whole body, the whole family, whereas specialists often look just at the one body system
- Having a genetic diagnosis can help customize and optimize healthcare plans now and in the future
- Don't be afraid/closed off about genetics—prepare yourself for varied reactions when you're gathering family history but know that it is important for getting a complete picture of what could affect your child's development
- "Genome Sequencing" is powerful AND--you need a knowledgeable and experienced provider with you that can help interpret that data, Don't plan to try it alone. You don't want an \$\$\$ bill and no one to interpret.
- Some parents give up because wait lists for genetics is so long. Explore different options including telehealth
- Sooner is better than later....finding a genetics provider for an adult can be even harder than a pediatric geneticist

[FOR MORE INFORMATION:](https://nymacgenetics.org/patients-and-families/getting-a-diagnosis/)

<https://nymacgenetics.org/patients-and-families/getting-a-diagnosis/>





FAMILY HISTORY AND GENETIC DIAGNOSIS

Knowledge of Family History can be Important

According to the Centers for Disease Control, knowledge of family history can be important for determining a child's health risks

It can help make a diagnosis, if a child presents with symptoms, or suggest strategies families can employ to minimize or postpone the onset of certain diseases.

Always take your family history and your genetics history with you to other doctors

Resources and support from P2P NYS: Healthcare Notebook from P2P- check out ptopnys.org for upcoming trainings



Other FH tools

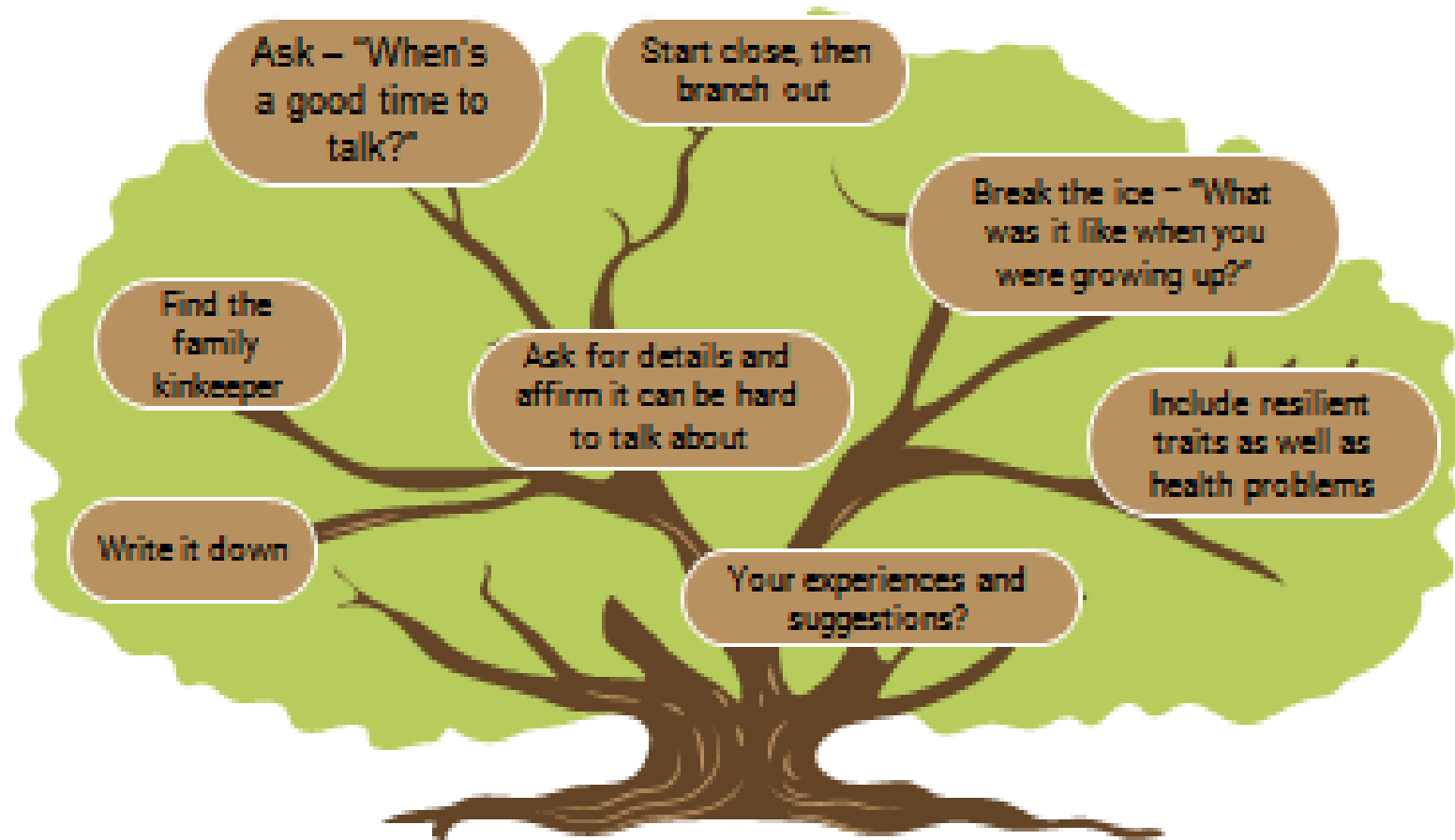
<https://nymacgenetics.org/patients-and-families/family-history/>

- + [How to collect health history: What's important?](#)
- + [How family history promotes wellness: Who can I talk to?](#)
- + [Ten Reasons to Collect Family Health History](#)
- + [Ten Things You Can Do To Use Genetic Health Information Constructively](#)

Family History Resources

- [Deaf Community- How to Collect Family Health History: What's Important? Youtube Video](#)
- [Genetic Alliance Family Health History](#)
- [CDC resources on family health history](#)
- [My Family Portrait](#)
Developed by the Surgeon General, My Family Portrait is a tool that can help families collect family health histories. It contains information and a form to fill out about your family health history, helps families understand their genetic inheritance and risk for disease, can be used to partner with medical professionals, and comes in several languages.
- [CDC Podcast: Family History: An Early Warning for Your Child](#)
This 10-minute podcast, featuring Dr. Paula Yoon and Dr. Tracy Trotter, discusses why a Family Health History is important for your child's health, how it may be used by your doctor, and how to obtain a family health history.
- [NIH Senior Health: Creating a Family Health History](#)

Learning about your family tree



WHAT ARE EXAMPLES OF WHAT A FAMILY MIGHT GET OUT OF A GENETICS APPT?

➤ **Input about**

- **What might be causing the differences they are observing**
- **Things that are unlikely to be the cause**
- **Genetic tests to consider**

➤ **Information about**

- **Any clues in the family history that suggest a possible genetic condition**
- **Whether other members of the family might have the same differences**
- **Potential treatments or therapies**
- **Next steps and what to expect in the future**
- **Recommendations for other doctors or professionals that might be helpful**
- **Support resources for school**
- **Connections to other families, support groups, and family organizations**
- **Recommendations for reliable resources for information**
- **Opportunities to ask questions**

Every appointment is different, depending on the needs of the family and the information that is available that day

CONSIDERATIONS IN GENETIC TESTING

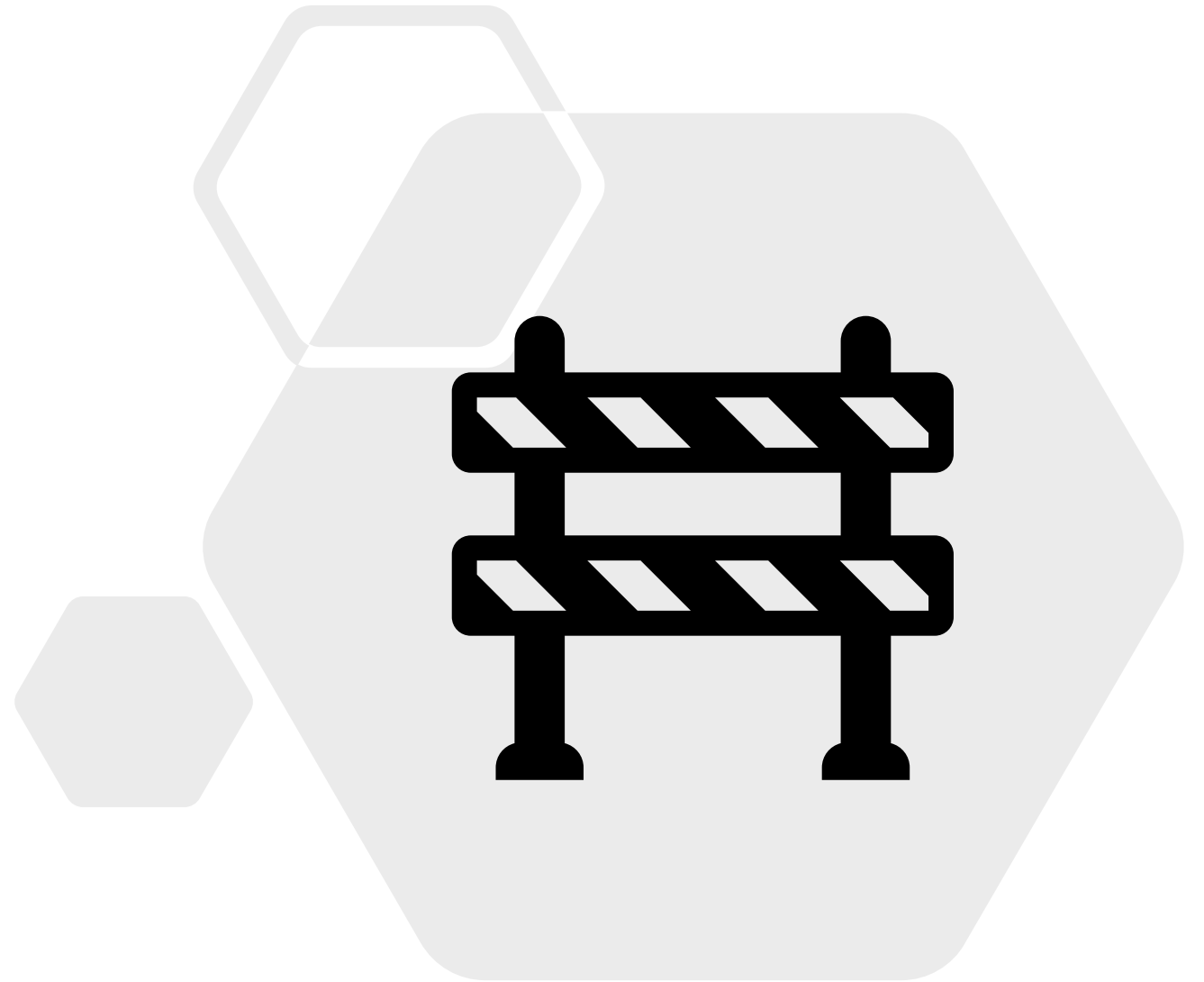
- Karyotype
- SNP/chromosomal microarray
- Single gene/mutation
- Next generation sequencing (NGS) panel
- Whole exome sequencing (WES)

Whole genome sequencing (WGS) - at horizon

WES/WGS are powerful, but you need a provider that can help interpret the data



What barriers have you run into trying to get a genetic diagnosis?



WHAT RESOURCES DOES NYMAC HAVE TO SUPPORT FAMILIES?



- Video Projects
- Webinars, Trainings, Annual Meeting
- Red Flags Documents
- Collaborating with Primary Care
- Resource Identification and Development

Spanish Genetic Services Video



[Genetic Screening Resources for Families | Heartland Genetics Services Network \(heartlandcollaborative.org\)](https://www.heartlandcollaborative.org/genetic-screening-resources-for-families)

Servicios de genética en Puerto Rico

Adiestramiento virtual para familias
OCTUBRE 6 Y 8 2021
9AM-11AM

Sólo 50 espacios disponibles

Las familias que participen ambos días recibirán un estipendio de \$75

Aprende:

- Conceptos básicos de genética
- Recursos disponibles en Puerto Rico
- Estrategias de liderazgo y comunicación
- Cómo participar e iniciar grupos de apoyo
- Consejos para mejorar la comunicación con los proveedores de salud

Regístrate ya!

 NYMAC
www.nymacgenetics.org
 FAMILY VOICES®
www.familyvoices.org

Pediatric Genetics Referrals: When to Refer to Genetics

- Genetic risk assessment and testing can be helpful in aiding in the care of individuals with a personal or family history of genetic conditions.
- Some genetic conditions are inherited through either **males or females**, while others can be inherited through **both males and females**.
- Those with an unknown or limited family history can still be referred to genetics for evaluation.
- Genetic test results can:
 - Impact treatment and management recommendations
 - Inform unaffected individuals of possible future risks to themselves or future children
 - Guide appropriate screenings

General Referral Guidelines for Pediatric Indications

A genetics evaluation should be considered for individuals with any of the following:

- A **known genetic pathogenic variant/mutation identified** in an individual or family member
- A **known or suspected genetic disorder, birth defect, or chromosomal abnormality**
- A **newborn** with any of the following:
 - Abnormal newborn screening test result
 - Congenital hypotonia or hypertonia
 - Unexplained intrauterine growth retardation
- A **newborn, infant, or child** with any of the following:
 - A **single major anomaly, or multiple major and/or minor anomalies**
 - **Dysmorphic features** that are not familial
 - **Failure to thrive**
 - A **known metabolic disorder** or symptoms of a metabolic disorder (Note: A normal newborn screening result does not rule out all metabolic disorders)
 - **Abnormal brain MRI findings**
 - **Unusual growth patterns**
 - **Evidence of a connective tissue disorder**
 - **Congenital eye defects or blindness**
 - **Significant hearing loss or deafness**
 - **Cardiomyopathy** not secondary to a viral infection
 - **≥ 6 café-au-lait macules** at least 0.5 cm in diameter
 - **Unusual skin findings** such as multiple types of lesions, multiple lipomas, numerous hypo- or hyperpigmented lesions, or albinism
 - **Bilateral or multifocal malignancies**
- A **child** with:
 - **Developmental delay**
 - **Intellectual disability**
 - **Autism Spectrum Disorders**
 - **Immunodeficiency**
 - **Progressive muscle weakness**

Full referral guidelines are referenced on the back of this handout. If you are concerned about a patient's personal or family history, a genetics professional can help determine if further risk assessment and/or genetic testing is indicated.

[When to refer patient to Genetics | NYMAC | Regional Genetics Network \(nymacgenetics.org\)](https://www.nymacgenetics.org)

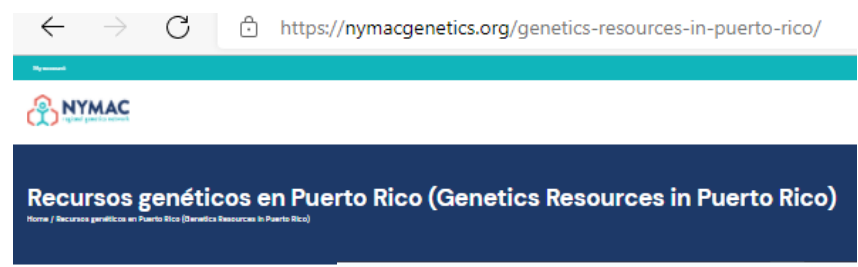
Also available in Spanish

[Your Genetics Appointment – YouTube](https://www.youtube.com/watch?v=...)
Also available in other languages





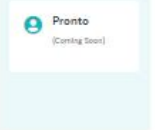
NYMAC WEBSITE



Para abordar las necesidades únicas de las familias en Puerto Rico, estamos colaborando con un grupo diverso de partes interesadas, entre otros se reúne en el transcurso de varios años para compartir sus perspectivas y experiencias sobre las barreras que enfrentan las familias cuando necesitan acceder servicios de genética en Puerto Rico. (To address the unique needs of families in Puerto Rico, we are collaborating with a diverse group of stakeholders. This group will meet over the course of several years to share their perspectives and experiences on the barriers families face when they need to access genetic services in Puerto Rico.)

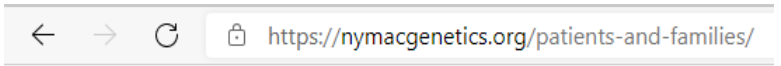


Conoce al equipo de NYMAC en Puerto Rico (Meet the Puerto Rico team)



Recursos útiles para familias en Puerto Rico (Useful resources for families in Puerto Rico):

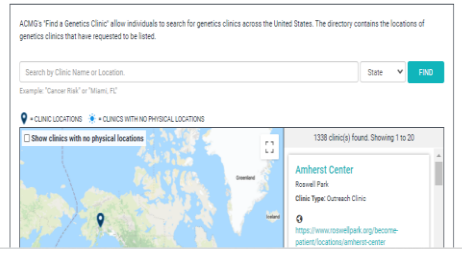
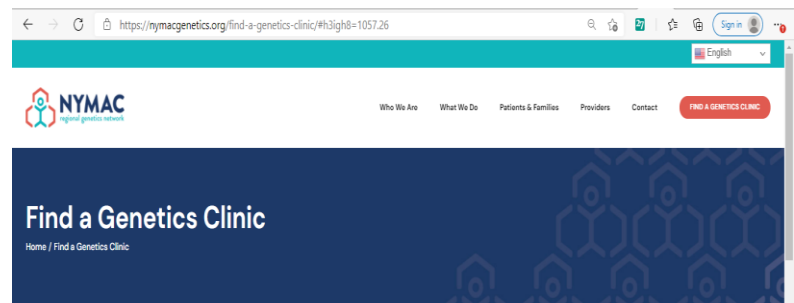
- Hechos básicos de la genética (Basic Genetics)
- Información sobre citas con proveedores de genética (Information about Appointments with Genetics Providers.)
- Información sobre pruebas genéticas (Genetic Testing Information)
- Información sobre condiciones genéticas (Information about Genetic Conditions)
- Información sobre cáncer y genética (Information about Cancer and Genetics)
- Información sobre Servicios Genéticos en Puerto Rico (Information about Genetic Services in Puerto Rico)
- Información sobre organizaciones de apoyo a las familias y consejos de comunicación (Information about Family Organizations and Support, Communication Tips)
- Genética durante el embarazo (Genetics During Pregnancy)
- Genética y condiciones relacionadas con el corazón y la sangre (Genetics and conditions related to the heart and blood)



Patients & Families

Home / Patients & Families

- 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



THE NYMAC TEAMS

(10-15 Members)

- Genetics providers (Geneticist, Genetic Counselor, APNG, Metabolic Dieticians, etc)
- Family Leader (eg: F2F, P2P, support groups, etc)
- Self/Family Advocate (family living with genetic condition)
- Consumer/Family Member representing an underserved community in the geographic area (Amish, Native, etc)
- Pediatrician
- Primary Care Providers
- Representative from GC training programs
- Representative from Genetics Residency programs
- Representative from state genetics groups
- Representative from Maternal Child Health
- Medicaid representative
- Representative from Public Health-NBS
- Representative from Public Health-Title V
- Representative from State AAP or other state groups
- Representative from Early Childhood Education
- Representative from relevant industries (eg: medical foods and formula companies)
- Representative from Insurance industry
- Representative from Pharma

Meet the NY NYMAC Team

<p>Noura Abul-Huzn Division Chief, Genomic Medicine, Icahn School of Medicine at Mount Sinai</p>	<p>Amanda Bergner Program Director/Genetic Counselor, Columbia University/Genetic Counseling Graduate Program</p>	<p>Katie Bergstrom Genetic Counselor, Weill Cornell Medicine</p>
<p>Naomi Brickel Parent, Community Support and Public Policy/Westchester Institute for Human Development</p>	<p>Heather Brumberg Neonatologist, New York Medical College and Marie Perle Children's Hospital at Westchester Medical Center</p>	<p>Michele Caggana Geneticist, New York State DOH/Wadsworth Center-NBS</p>
<p>Sharon Chezma Executive Director, Mothers and Babies Perinatal Network</p>	<p>Cynthia Cortright Director of Medical Services & SNAR Broome County DSS</p>	<p>Luba Djurdjovic Program Director/Genetic Counselor, Penn Genetics</p>
<p>John Glanonne Assoc. Medical Director / CMD, United Health Services Hospitals/ Delaware Valley Hospital</p>	<p>Douglas Hamilton Program Manager, Family Support/Community Family Services, Saint Regis Mohawk Tribe</p>	<p>Isha Kalia Genetic Counselor, Columbia University/Genetic Counseling Graduate Program</p>
<p>Lara Madison Program Director, WELLOW Initiative, Maternal Infant Community Health Collaborative/Albany County Dept. Health</p>	<p>Kendra Muckie Medical Assistant Specialist 2, Bureau of Medical, Dental and Pharmacy Policy/New York State DOH</p>	<p>Eliza Muftic Director, Developmental-Behavioral Pediatrics Fellowship Program, Rose F. Kennedy Children's Evaluation and Rehabilitation Center/The Children's Hospital at Montefiore</p>
<p>Lin Perry Project Director, Parent to Parent of NY State</p>	<p>Monisha Sebastin Genetic Counselor, The Children's Hospital at Montefiore</p>	<p>Emily Soper Genetic Counselor, Icahn School of Medicine at Mount Sinai</p>
<p>Penny Stringfield Account Executive (Parent, Ad Elements)/Parent</p>	<p>Mabel Thomas Genetic Counselor, Sema4 Laboratory</p>	<p>Nori Williams Genetic Counselor, PWN Health</p>
<p>Monika Zak Program Director/Genetic Counselor, Long Island University/Genetic Counseling Graduate Program</p>	<p>Randi Zinberg Program Director/Genetic Counselor, Icahn School of Medicine at Mount Sinai/Genetic Counseling Graduate Program</p>	

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.










<https://nymacgenetics.org/newyork/>
We can help!

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.



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 \$841,455 with 3 percent financed with non-governmental 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.

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
-  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
-  Your child having multiple unexplained issues

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

NY:
Infographic,
Social Media
Campaign
and Pocket
Cards to
address key
family
questions





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

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<https://nymacgenetics.org/>



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nymacgenetics.org

facebook.com/NYMACGenetics

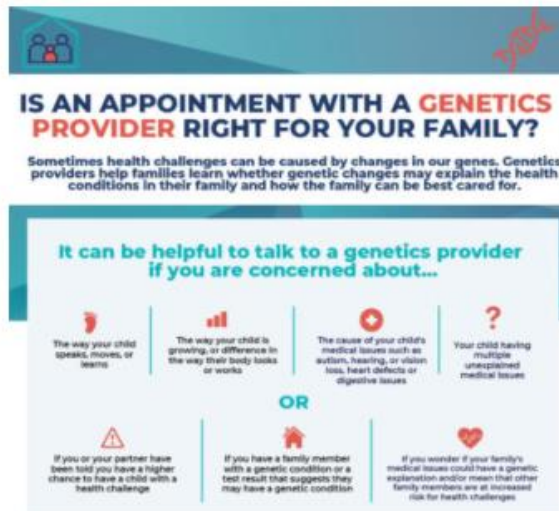
[tk1vNYMACGenetics](https://www.youtube.com/channel/UCk1vNYMACGenetics)

<https://nymacgenetics.org/newyork/>

Resources for Genetics in New York

Home / Resources for Genetics in New York

Approximately 16% of children in NYS have one or more special health care needs. Across NYS, there are almost 150 genetics clinics to help answer your family's questions. To address the unique needs of families across NY, a diverse group of stakeholders met over the course of a year to share their perspectives and experiences about the barriers families face when trying to access genetic services in NYS.



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[DOWNLOAD PDF](#)

[DESCARGAR PDF EN ESPAÑOL](#)



Meet the New York team

[LEARN MORE](#)

Common Questions For Families in NY

Q. How do I learn more about how my child's development compares to other children?

A. Use these tools to track a child's development:

<https://www.cdc.gov/ncbddd/actearly/milestones-app.html>



Q. Where can I find support?

A. Parent to Parent of New York State has a supportive network of families connect you to resource and support and help prepare you for next steps:

<http://parenttoparentnys.org/index.php/site>



Q. How do I find a genetics provider?

A. Your family's doctors can help you find a genetics provider. This tool searches for genetics clinics nationwide, including clinics that offer telemedicine:

<https://nymacgenetics.org/find-a-genetics-clinic>



Q. How do I learn about insurance coverage?

A. Most insurance plans will cover genetic services. If you need help with your insurance In New York State, CHA is a free statewide network of organizations helping families obtain and use health insurance to access the health care they need:

<https://communityhealthadvocates.org/>



Q. How do I best care for my child as they get older?

A. As a child gets older, their health needs and screening needs, their provider, and their independency may change. Here are some useful resources:

<https://healthytransitionsny.org/>



Useful Resources for Families in NY

Find a Genetics Provider in NY: Find a Genetics Clinic – NYMAC – Regional Genetics Network (nymacgenetics.org)

Parent to Parent of NYS: Parent to Parent of New York State builds a supportive

THE NY NYMAC TEAM



Moving From Pediatric to Adult Health Care

ABOUT

GUIDES


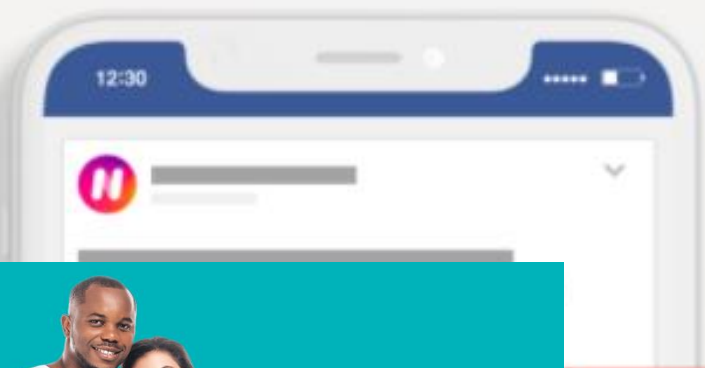
VIDEOS


TOOLS

Transition Skills Checklist

- Scheduling an Appointment
- Getting Health Insurance
- Deciding About Guardianship
- Speaking up at the Doctor's Office
- Understanding Your Disability
- Managing Medications
- Keeping a Health Summary
- Looking Into Service Coordination
- Setting Health Goals
- Finding Community Resources







 **NYMAC**
regional genetics network


it can be helpful
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provider** if you are
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→





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

 →



<https://nymacgenetics.org/events/>

4/5/22 and 4/6/22



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

Who We are
The New York-Mid-Atlantic-Caribbean (NYMAC) Regional Genetics Network is one of seven Regional Genetics Networks in the country funded by a federal (HRSA) grant. Our region includes DC, DE, MD, NJ, NY, PA, PR, USVI, VA and WV.

Free CME / CEU were awarded for the 2021 Annual Conference



Questions?: nymac@ferre.org

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

Key Themes:

- Collaboration among stakeholders
- Genetics in Primary Care (*including transition*)
- Public Health and Genetics
- Designing New Models of Genetic Services

Recordings of the 2021 meetings are now available for free and for CME/CEU

Two Day Virtual Meeting May 4th and 5th

Expanding Access to Genetic Services:

Collaboration, Communication & Connection

- Join a dynamic group of Families, Advocates, Healthcare Providers, and Public Health Professionals as we share, learn and plan to effect positive changes in access to genetic services.
- View the agenda and find additional resources about genetics topics, family perspectives, and other NYMAC Projects: nymacgenetics.org

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CME / CEU at No Cost
This activity has been approved for AMA PRA Category 1 Credit™. This event has been submitted to the National Society of Genetic Counselors (NSGC) for approval of Category 1 CEUs. The American Board of Genetic Counseling (ABGC) accepts CEUs approved by NSGC for purposes of recertification. Approval for this requested CEUs and Contact Hours is currently pending.

Space is Limited! No Cost To Register

QUESTIONS? nymac@ferre.org

Spanish Translation and Closed Captioning Provided



Trainings and webinars on transition topics

- Healthcare Notebook
- Empowerment for Education: Schools and Teens in Healthcare Transitions
- Benefits and Entitlements
- Nuts and Bolts of Telehealth
- Education transition topics

<http://parenttoparentnys.org/news/statewide-events/>

A conceptual image featuring two round glass fishbowls on a dark blue surface against a dark blue background. The left fishbowl is filled with water and contains several goldfish. One goldfish is captured mid-jump, having just left the water, with a splash of water trailing behind it. The right fishbowl is empty. A thin white horizontal line is drawn across the middle of the image, passing between the two fishbowls. The text "Other transition resources" is written in a large, white, sans-serif font across the bottom half of the image, overlapping the fishbowls and the white line.

Other transition resources

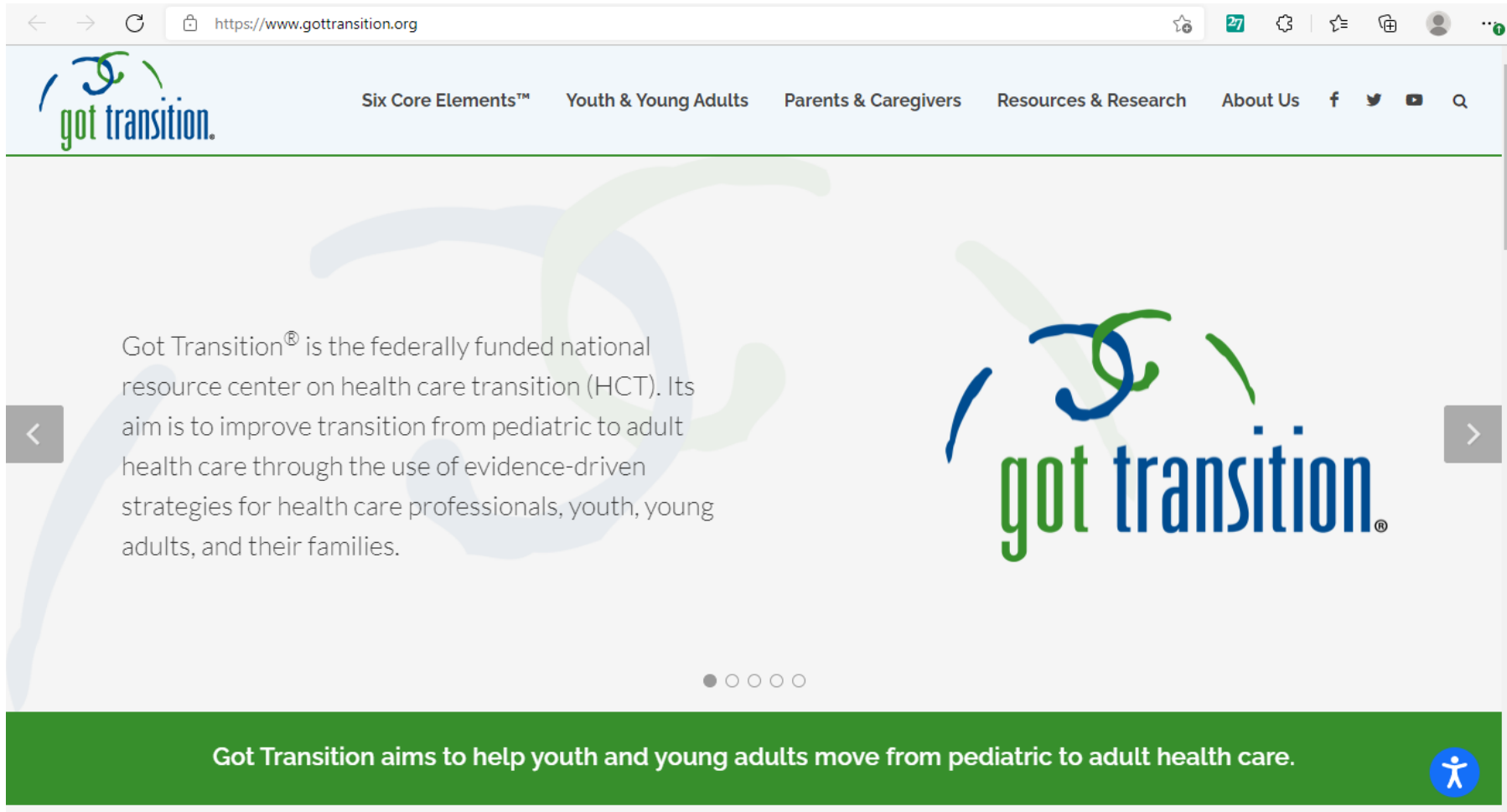


Health Care Skills [Checklist], Revised 2010. Adolescent Health Transition Project, University of Washington Center on Human Development and Disability
<https://depts.washington.edu/healthtr/documents/healthcareskills.pdf>

Healthy Transitions NY -this website is for youth with developmental disabilities ages 14-25 years, family caregivers, service coordinators, and health care providers. HealthyTransitionsNY.org teaches skills and provides tools for care coordination, keeping a health summary, and setting priorities during the transition process. It features video vignettes that demonstrate health transition skills and interactive tools that foster self determination and collaboration. This website is ADA accessible and is available with audio for non-readers and in Spanish language translation.
<http://www.healthytransitionsny.org/>

Got Transition - <http://www.gottransition.org/>

Got Transition



The screenshot shows the homepage of the Got Transition website. At the top left is the NYMAC logo. The main navigation bar includes links for "Six Core Elements™", "Youth & Young Adults", "Parents & Caregivers", "Resources & Research", and "About Us", along with social media icons for Facebook, Twitter, and YouTube. The main content area features a large, light-colored graphic of a person's silhouette with a DNA helix. On the left, a text block describes the organization's mission. On the right, the "got transition." logo is displayed. A green banner at the bottom contains a summary statement and a person icon.

https://www.gottransition.org

got transition.

Six Core Elements™ Youth & Young Adults Parents & Caregivers Resources & Research About Us

Got Transition® is the federally funded national resource center on health care transition (HCT). Its aim is to improve transition from pediatric to adult health care through the use of evidence-driven strategies for health care professionals, youth, young adults, and their families.

got transition.®

Got Transition aims to help youth and young adults move from pediatric to adult health care.

Care Coordination and Medical Home Resources

<https://nymacgenetics.org/patients-and-families/care-coordination-and-medical-home/>

- [Nemours: Children's Health System](#)
 - [Becoming an Adult: Deciding Where to Live](#) (Youtube Video)
 - [Becoming an Adult: Legal and Financial Planning](#) (Youtube Video)
 - [Becoming an Adult: What Can I Do After High School?](#) (Youtube Video)
 - [Becoming an Adult: Taking Responsibility for Your Medical Care](#) (Youtube Video)



QUESTIONS?

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