GPCI

GENETICS IN PRIMARY CARE INSTITUTE

geneticsinprimarycare.org

*A cooperative agreement between the American Academy of Pediatrics and the Health Resources and Services Administration, Maternal and Child Health Bureau*

# Genetics in Primary Care Institute: Co-Management Between Primary Care and Genetic Service Providers


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*Kansas City, MO*


Heartland Genetics Collaborative Meeting

**April 25, 2014**

# Acknowledgments


- The Genetics in Primary Care Institute (GPCI) is a three-year cooperative agreement between the American Academy of Pediatrics (AAP) and the Health Resources & Services Administration (HRSA)/Maternal & Child Health Bureau (MCHB), Genetic Services Branch

- June 1, 2011—May 31, 2014

# Impetus for the GPCI

- Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) - recommendations in 2009 workshop provided blueprint for GPCI
- Documented gaps exist in PCPs' knowledge, attitudes, and practice
- Advances in genetics and genomics continue, prompting more demand, while workforce shortages among genetic professionals grow
- Strategies and tools are needed to improve PCPs' role in providing genetic services

# Genetics in Primary Care Institute

**Vision:**
**To improve primary care providers' knowledge and skills in the provision of genetic medicine**

# Goals of the GPCI

**Quality Improvement**

- **Develop and test strategies** to integrate genetics into the medical home

**Technical Assistance Center**

- Provide **education** and **technical assistance** to a wide audience of PCPs

**Resident Education**

- Embed genetic education into the **future pediatric PCP workforce**

# Roles of the PCP

- **Evaluate** through screening and surveillance
- **Educate** patients and their families
- **Explain** the results
- Make **appropriate referrals**
- **Coordinate care** with a subspecialist
- **Counsel** patients and families
- Provide **long-term follow-up** and care

## 7 Key Roles of the Primary Care Provider

**Evaluate through Screening and Surveillance**
Use family health history for primary prevention of chronic illness and to identify a patient's need for increased surveillance.

**Educate Patients and Their Families**
Discuss the importance of screening, early diagnosis, and how genetic tendencies may be present with an acute manifestation of disease.

**Explain the Results**
Review and discuss the meaning of screening, test results, and what to expect from genetic consultation and referral.

**Make Appropriate Referrals**
Provide information based on clinical history and ensure adequate follow-up for patients.

**Coordinate Care with a Subspecialist**
Initiate a co-management plan, including treatment and diagnostic testing when appropriate.

**Counsel Patients and Families**
Help them understand and adapt to the implications of a genetic diagnosis.

**Provide Long-Term Follow-Up and Care**
Continue to support patients and families and provide primary care through an ongoing relationship within the medical home.

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# Integrating Genetics into Primary Care Practice

# QUALITY IMPROVEMENT PROJECT

# Project Oversight

- GPCI Project Advisory Committee
- Multidisciplinary Expert Group
  - Amy Driscoll, MD, FAAP
  - Beth Tarini, MD, MS, FAAP
  - Wendy Chung, MD, PhD, FACMG
  - Abdallah F. Elias, MD, FAAFP, FACMG
  - Kerry Jedele, MD, FACMG, FAAP
  - Ruth Gubernick, MPH
  - Ingrid Larson, MSN, RN, CPNP
  - Beth A. Pletcher, MD, FAAP, FACMG
  - Michael Rinke, MD, FAAP
  - Lisa M. Vasquez, MPA

# Needs Assessment

2012 Survey of AAP QuIIN members (n=88)

- Less than half of pediatricians reported feeling competent providing services related to genetics and genomics
- 60% did not have adequate resources or information to determine which genetic tests to order
- Lack of knowledge of existing resources (eg, NBS ACT sheets)
- 100% of pediatricians agree/strongly agree that taking a FH is important for assessment of predisposition to disease
- EHRs lack functionality for recording FH information
- Less than 1/3 gather comprehensive FH from their patients

Rinke, M, Mikat-Stevens, N. Saul, R, Driscoll, A, Healy, J, Tarini, B. 2013. Genetic Services and Attitudes in Primary Care Pediatrics. *Am J Med Gen*. Part A 9999:1–7.

# Objective and Goals

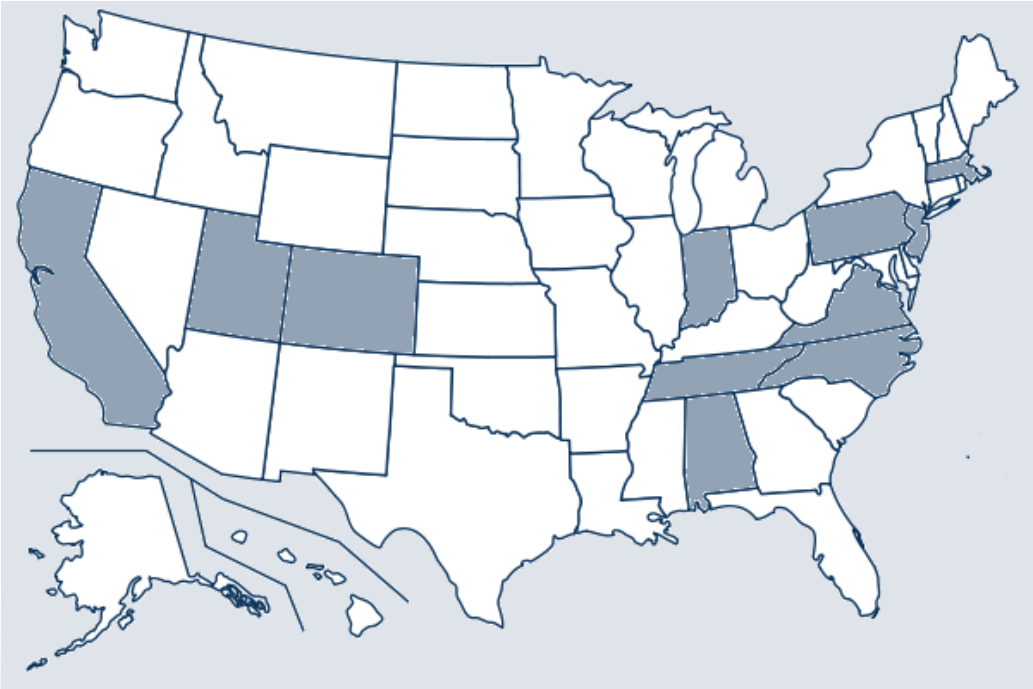
Test tools and strategies related to the integration of genetics into pediatric primary care

Project Goals

1. Eliciting **family history** as part of the health supervision visit
2. Improve the delivery of care for **pediatric patients with genetic conditions**
3. Develop policies and **improve office systems** to meet the first two goals of the project

# Project Participation

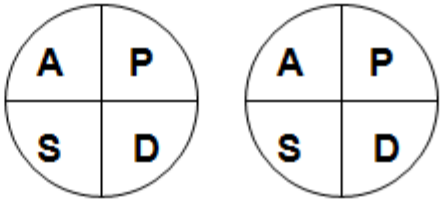
- 13 teams in 11 states serving 130,000 pediatric patients annually
- Practice teams (3 people total) include a lead physician, 1-2 other clinicians, nurse or assistant staff person
- Participated in 6 months of data collection regarding project goals



**Practice demographics:**

- All use an EHR
- One family physician
- Diverse range of practice type, geographic setting, and patient population

# QIP Timeline and Overview

| Application Process: | Prework: | Learning Session 1 March 8-9, 2013 | Action Period: | Learning Session 2 November 8-9, 2013 | Evaluation: |
|---|---|---|---|---|---|
| • Form core improvement team and determine roles of each member<br>• Attend informational call on October 1 or 11<br>• Complete project application | • Participate in prework call on December 18 (8 am CT) or 20 (11 am CT)<br>• Sign Consent Form<br>• Complete baseline data<br>• Assess current practice and systems<br>• Create a storyboard<br>• Make travel arrangements for Learning Session 1 | | • Participate on conference calls<br>• Collect monthly data (chart review, registry review, and narrative report)<br>• Test changes using PDSA cycles<br>• Provide feedback on tools<br>  | | • Conduct 6 month post-project evaluation on sustainability and continued improvement<br>• Qualitative phone interviews<br>• Submit final chart review and registry review data |
| Oct – Nov 2012 | Dec 3, 2012-Jan 30, 2013 | | April-Sept 2013 | | March 2014 |

## Education and Mentorship Provided:

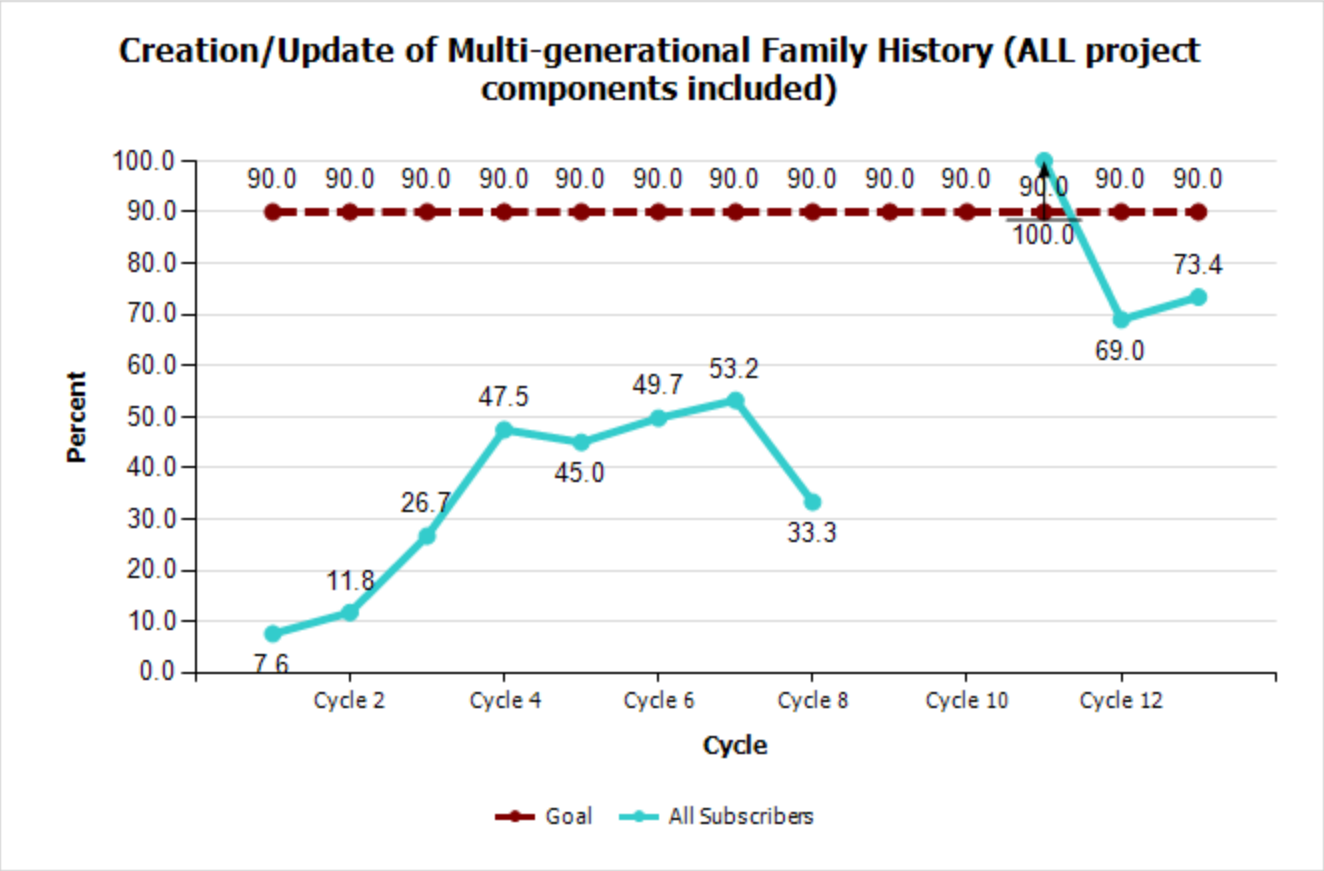
- Change Package with resources, tools, and information
- Bi-monthly clinical team coaching calls
- Access to a multidisciplinary Expert Group and genetic professionals
- Two in-person educational sessions
- CME conference, webinars, handbook, and other ad hoc resources

# Family History

Steps Towards Collecting FH

1. Obtain buy-in
2. Test FH tools, strategies to integrate into workflow
3. Discuss FH with families
4. Identify red flags
5. Follow-up with identified risk
6. Evaluate your FH tool
7. Maintain and update FH annually

# Results – Family History



# Best Practices – Family History

- Obtain buy-in from all providers and clinic staff
  - Reiterate value to all, even front desk staff handing out forms
- Test various tools and approaches to collect FH
- Begin collecting FH at new patient or 2-month visit, goal to have comprehensive FH by 2 yrs.
  - Request information from family members; others accompanying child to sick and well-check visits
- Contact genetic professionals with concerns or suspicions
- Ask family members if they have any FH concerns
- Notice red flags, even negative (everyone is "healthy")
- Work with EHR vendor or IT dept. to model FH screen in EHR from paper form to facilitate data collection and entry

# Identifying Patients with Suspected Genetic Conditions

Steps Towards Improving Patient Care

1. Recognize Clinical Red Flags
2. Identify and Follow-Up with Patients Identified at Risk
3. Talk to Parents about an At-Risk Family Health History or Genetic Referral
4. Develop Relationships with Genetic Professionals
5. Review Indications for Possible Referral for a Genetic Evaluation
6. Order Appropriate Genetic Tests

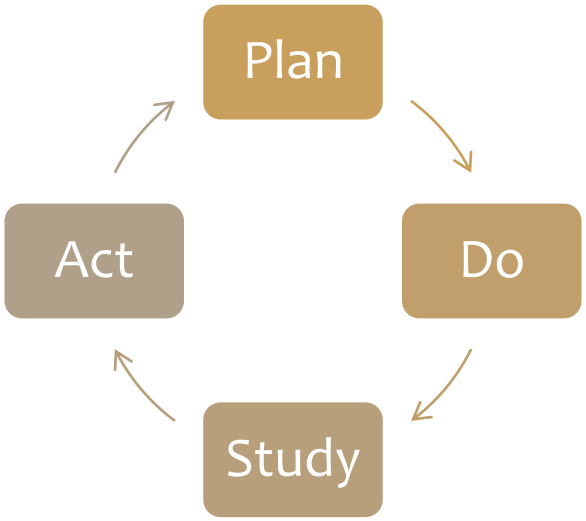
# Providing Appropriate Care for Patients with Genetic Conditions

Steps Towards Improving Patient Care

1. Implement Systems to Improve Genetic Services
2. Create a Patient Registry
3. Follow the Health Supervision Guidelines
4. Provide Family-Centered Care

# Steps Towards Implementation

1. Identify patients with diagnosed genetic conditions; create a patient registry
2. Create aim statements / goals to improve procedures
3. Review patient registry data, re-evaluate aims



# Size of Practice Registries for Children with Genetic Conditions

In January 2013:

- < 50 patients = 4 practices
- 51-150 patients = 6 practices
- > 1000 patients = 3 practices

In September 2013:

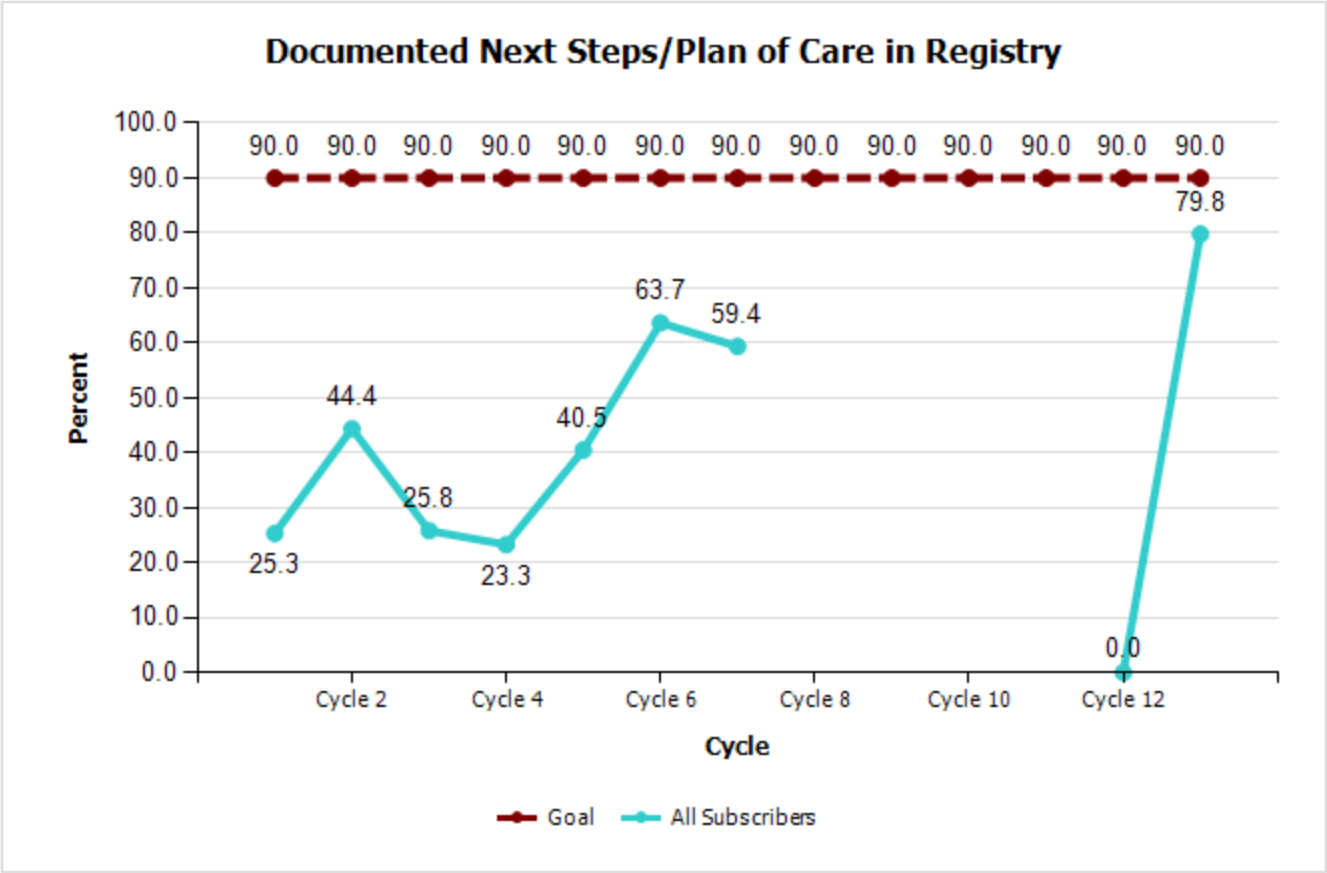
- < 50 patients = 3 practices
- 51-150 patients = 5 practices
- 151-999 patients = 4 practices
- > 1500 patients = 1 practice

# Coordinating Care for Patients with Genetic Conditions

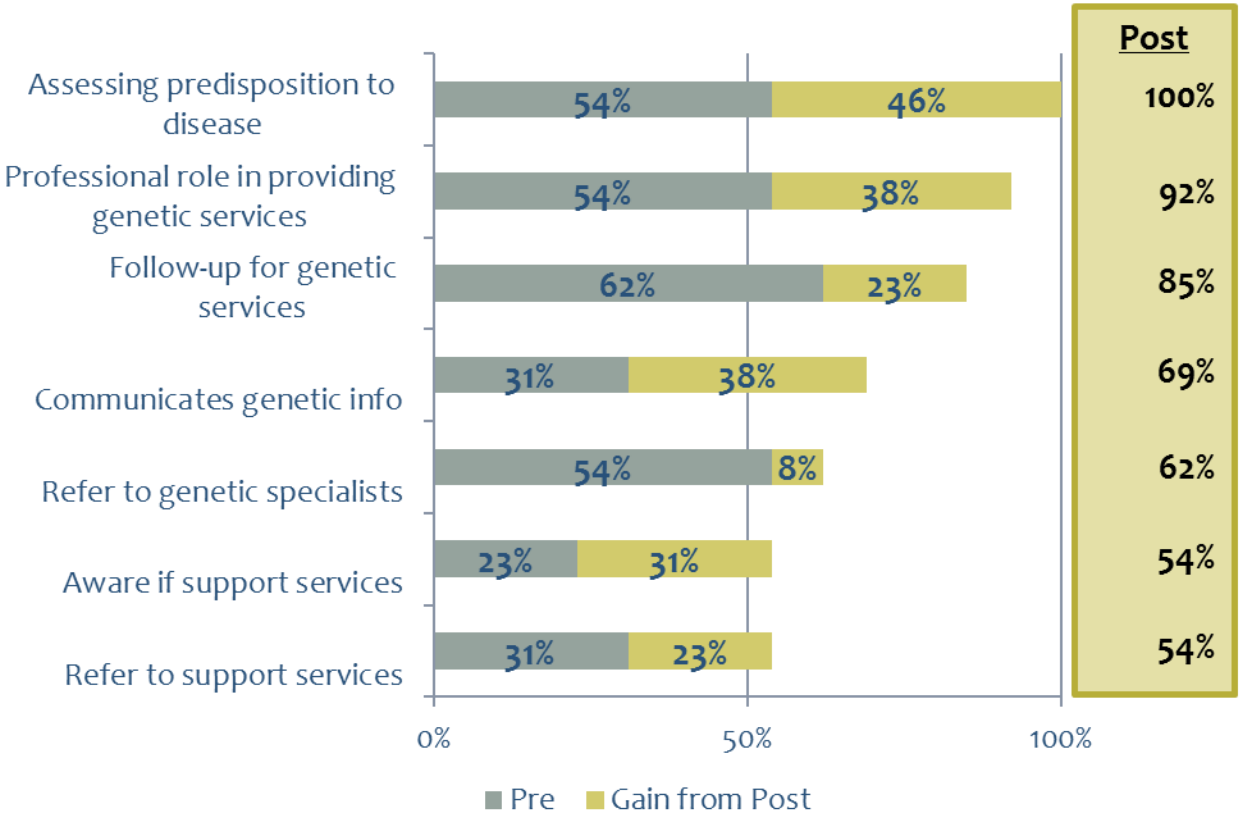
Steps Towards Improving Patient Care

1. Improve Processes to Co-Manage Care with Specialists
2. Obtain Current Emergency Plans (if applicable)
3. Obtain Current Emergency Letters (if applicable)
4. Plan for Transitions to Adult Care
5. Discuss Palliative Care

# Results – 6 month post-project



# Knowledge
# Pre vs. Post Comparison




All knowledge areas assessed in the pre-survey saw at least some improvement in the post-survey, with the importance of FH, role in providing genetic services, and communicating genetic info measures seeing the highest gains.

# Policies and Procedures for Patients with Genetic Conditions

| *Practice has a standard process (written or not written) for…* | Pre | Post | Δ from pre |
|---|---|---|---|
| **Tracking genetic referrals made** | 38% | 85% | **47%** |
| **Identifying patients with a defined genetic condition** | 23% | 77% | **54%** |
| **Tracking children with a defined genetic condition** | 23% | 77% | **54%** |
| ***Identifying* genetic patients who are behind schedule for preventative services** | 23% | 69% | **46%** |
| ***Contacting* genetic patients who are behind schedule for preventative services** | 38% | 69% | **31%** |
| **Transition to adult care discussion with genetics patients by age 12** | 15% | 62% | **47%** |
| **Co-managing care genetics patients** | 8% | 31% | **23%** |
| **Obtaining emergency plans from specialists** | 15% | 31% | **16%** |

Most practices established processes or written protocols around tracking and identification of patients with a defined genetic condition

Fewer practices established processes or written protocols around emergency plans and co-managing care

# Barriers to Implementation

| | Barrier | % selecting 3 or 4 (significant barrier) | Average Rating |
|---|---|---|---|
| **Overall Project** | Time it takes to develop new policies and procedures | 69.2% | 3.0 |
| | Time it takes to implement new policies and procedures | 69.2% | 2.9 |
| | Time it takes to add these components to the health supervision visit | 46.2% | 2.4 |
| **Family History Collection** | Limitations of the family history tools/screens in EHR | 69.2% | 2.7 |
| | Time required to enter the family history information into the EHR | 46.2% | 2.5 |
| **Providing Care for Patients with Genetic Conditions** | Difficulty in managing patient registry | 69.2% | 2.7 |
| | Difficulty in establishing a recall system for patients | 46.2% | 2.2 |

# Genetic Mentorship Program

**Goal: To increase partnerships between PCP and genetic professionals at the local / regional level**


**Format:**

- **Who:** A geneticist or genetic counselor paired with each practice from their region
- **What:** Meet monthly via phone, email, or in-person
- **Purpose:** Share information and resources, discuss patient cases, facilitate relationships

# Case Example: Mentorship Program

**Who:**

- PCP - Nassim and Associates (Indiana)
- Genetic Counselor - Cecilia Rajakaruna (Louisville, Kentucky)

# Case Example: Goals

1. Educating allied health staff on genetic conditions and FH
2. Tracking patients with genetic d/o
3. Integrating FH into the EHR
4. Working on care plan / creating care plans for patients
5. Developing policies and processes for genetic referrals
6. Connecting with local geneticists and allied health professionals

# Educating Allied Health Staff

- Discussing genetics in the practice
- Talking with your genetics specialist
- Create small changes to incorporate into clinic workflow

# Tracking Patients/EHR

- Electronic Health Record (EHR)
- Registry

# Care Plans/Transition

- Co-Management
- Transition – the specifics related to this population
- Syndrome specific – health management guidelines

# Connecting with Specialists

- Exposure to genetics
- Meeting your local team
- Utilizing your local specialists as resources

# Genetics Referrals

Pediatric primary care provider should consider referral to a medical geneticist:

- Abnormal newborn screening results
- Developmental disorder or intellectual disability
- Blindness or deafness
- Presence of a known or suspected genetic condition or chromosomal abnormality
- Disorders of growth
- Structural or morphological variations
- Family history of a known or suspected genetic disorder, birth defect, or chromosomal abnormality

# Case Example: Results

- **Knowledge**
  - Appropriate utilization of services
  - Knowledge of genetic red flags
- **Attitude**
  - 100% of participants value a FH and will continue to improve there processes towards collecting, storing, and updating information
- **Behavior**
  - All practices have integrated a genetics family history screening into their practice
  - Practices' patient registries had an average of 300 children with heritable disorders who are now receiving improved care

# Case Example: Results

- **Systems**
  - "I had never heard of a genetic counselor prior to this project"
  - "Thanks to my mentor, I now have a relationship with my local genetics center and have resources to help me when considering a referral and improved relationship with specialists to co-manage care"
- **Patient Outcomes**
  - "If it hadn't been for this project, I never would have considered a referral to genetics without a definitive diagnosis"
  - "Positive FH screen results in identification of genetic conditions or referral of patient or family member to genetics"

# GeneticsinPrimaryCare.org

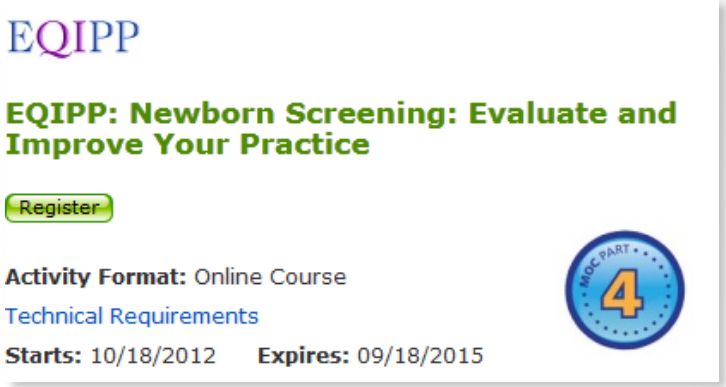
The clearinghouse for education and tools regarding genetics in primary care.

Informational destinations include:

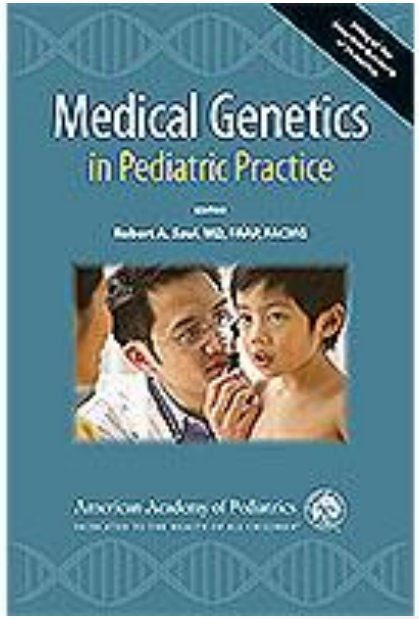
- What is genetics?
- Resources for Your Practice
- Provider Education
- Expert Video Testimonials
- And More!

# Additional AAP Resources

- Newborn Screening EQIPP Course
- "Dive into the Gene Pool" PediaLink CME Course
- Medical Genetics and Pediatric Practice: A Handbook
- PediaGene: AAP Genetics Screening Guide – Mobile Device Application







# Questions?

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- Genetic Testing
- Genetic Counseling
- Genetic Red Flags
- Family History in Primary Care

## What Is Genetics

Health-related genetic information has important social, emotional, and psychological implications for individuals and families, and as such play an important role within primary care practice.

More about Genetics

## For Your Practice

Primary care providers are in an ideal position to evaluate and treat patients with genetic diseases. For information and practical tools to assist you in incorporating genetics into your daily practice visit the "Integrating Genetics into

## For Your Patients

There are a number of resources available online to assist your patients in becoming familiar with topics such as family history and genetic testing, as well as provide support.

**www.geneticsinprimarycare.org**

# Contact Us

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www.geneticsinprimarycare.org

# Genetic Testing: A Guide for Primary Care

Knowledge in genetics has become an essential for all practicing physicians. Almost daily, the press and Internet have stories highlighting advances in genetics discovery and potential therapies. While many of these stories are somewhat sensationalized, primary care providers should have a strong background in the basics of genetics. Patients, parents and community partners rely on their primary care providers and staff to have accurate, thoughtful and evidence-based knowledge of genetics and genomic sciences. Kansas City is home to one of the largest ethnically and socioeconomically diverse populations in the state of Missouri.

May 15th, 2014: 5:30 -7:00pm, Don Chisholm, CMH

Must register!

Travel reimbursed by the HRGC!

Jennifer Kussmann – Genetic Counselor - Genetics

Ingrid Larson – Director – Beacon Program

Sarah Soden - Center for Pediatric Genomic Medicine

Funded by a grant from the AAP-GPCI for a Visiting Professorship.