

NYMAC  
Attn: Bonnie L. Fredrick, MS  
Wadsworth Center  
Empire State Plaza, Room E-297A  
P.O. Box 509  
Albany, NY 12201-0509

NYMAC was established in September 2004 as one of seven regional collaboratives in the United States. Its goal is to ensure that individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home. This construct should provide care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-effective. Membership to NYMAC and its work groups is open to anyone in the region interested in furthering its goals and objectives.

### Work Groups

**Consumer Education Work Group:** Ensure that information about genetics and newborn screening necessary for patients and their families to make informed decisions about the treatment of people with specific genetic conditions is available.

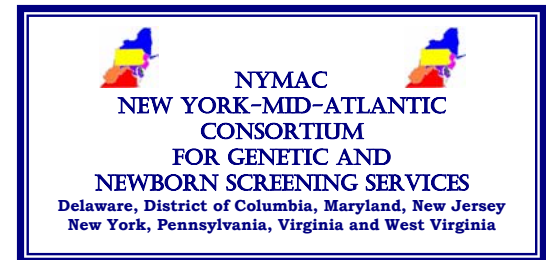
**Medical Home Work Group:** Develop collaborative partnerships among primary medical care providers, genetic and/or specialty care providers and health insurers to ensure continuity of medical care for people within a medical home identified with disease by the newborn screening program.

**Newborn Screening Standardization Work Group:** Standardize, as appropriate and possible, newborn screening panels in the region in light of the recommendations by the March of Dimes and the American College of Medical Genetics

**Professional Education Work Group:** Ensure that information about genetics and newborn screening necessary for primary medical care providers and medical insurers to make informed decisions about the treatment of people with specific genetic conditions is available.

**Telegenetics Work Group:** Develop and implement plans to connect infants who screen positive by newborn screening and people with special needs to genetic and specialty care providers through the use of telegenetics technology.

**Transitions Work Group:** Develop systems and collaborations that will enable adolescents and young adults with special needs to transition from pediatric medical care to adult medical care.



**Medical Home Seminar  
Friday, November 2, 2007  
10:00 a.m. – 5:00 p.m.**

\*\*\*\*\*

**Holiday Inn Philadelphia  
International Airport  
45 Industrial Highway  
Essington, PA 19029**

**The seminar is sponsored by NYMAC with the generous support of MARHGN (Mid-Atlantic Regional Human Genetic Network)**

## Purpose

The purpose of the seminar is to present experience and information about implementing medical home components and the benefits to the health and well-being of the patient and family. It will also ensure that the members of the NYMAC Medical Home Work Group, who will meet the next day, all share at least a basic level of knowledge about medical home.

## Seminar Agenda

- 10:00 Welcome**  
**Kenneth Pass, Renee Turchi**
- 10:15 Pediatric Practice-Oriented Medical Home**  
**Robert Ostrander**  
**Colleen Kraft**  
**Renee Turchi**
- 11:30 Pediatric Parent/Patient Partner Experience**  
**Lourdes Tate**  
**Kenya Beckford**  
**Sabra Townsend**
- 12:45 Lunch - provided**
- 1:30 Specialty Center-Oriented Medical Home**  
**Arti Pandya**  
**Robert Kaslovsky**  
**Lakshmanan Krishnamurti**
- 2:45 Adolescent/Adult Parent/Patient Partner Experience**  
**Fran Gallagher**  
**Ginger Davis**  
**Terri Hancharick**  
**Judy Brimer**
- 4:00 Discussion/Questions**  
**All speakers**
- 5:00 Adjourn**

## About the Speakers

**Kenya Beckford** is a parent of a child with sickle cell disease. She lives in Brooklyn, NY.

**Judy Brimer** is the parent of a young adult with a degenerative neurologic disease. She lives in Delaware.

**Ginger Davis** is the Director of the Sickle Cell/Thalassemia Patients Network in Brooklyn, NY. She has sickle cell disease.

**Fran Gallagher, MEd**, is the Executive Director of the Pediatric Council on Research and Education of the New Jersey Chapter of the American Academy of Pediatrics in Trenton, NJ. She is the parent of a young adult with special needs.

**Terri Hancharick** is the parent of a young adult with complex disabilities. She chairs the Adult Transition Committee of the Delaware Governor's Advisory Council for Exceptional Citizens.

**Robert Kaslovsky, MD**, is a specialist in the treatment of children with cystic fibrosis at West Virginia University in Charleston, WV.

**Colleen Kraft, MD**, is a pediatrician and the Chair of the Division of Community Pediatrics at Virginia Commonwealth University in Richmond, VA.

**Lakshmanan Krishnamurti, MD**, is the Director of the Comprehensive Hemoglobinopathy Program at Children's Hospital of Pittsburgh, PA.

**Robert Ostrander, MD**, is a family practitioner in Rushville, NY. He is a member of the New York Academy of Family Physicians and has participated in NYS medical home initiatives.

**Arti Pandya, MD, MBA**, is a metabolic specialist in the Department of Human Genetics at Virginia Commonwealth University in Richmond, VA.

**Kenneth A. Pass, PhD**, is the Director of the Laboratory of Molecular Screening Technologies at the New York State Department of Health in Albany, NY. He is the principal investigator for NYMAC.

**Lourdes Tate** is the parent of a child with methylmalonic aciduria and an advocate for children with special needs and expanded newborn screening in Pennsylvania.

**Sabra Townsend** is a parent of a child with special needs. She lives in Philadelphia, PA.

**Renee M. Turchi, MD**, is the Associate Medical Director at the Center for Children with Special Health Care Needs at St. Christopher's Hospital for Children in Philadelphia, PA. She serves as chair of the NYMAC Medical Home Work Group.

## Seminar Registration

E-mail form to [blf01@health.state.ny.us](mailto:blf01@health.state.ny.us);  
fax to (518) 473-1733 or mail to address on back.

Deadline October 16, 2007

Name: \_\_\_\_\_  
Degrees: \_\_\_\_\_  
Title: \_\_\_\_\_  
Address: \_\_\_\_\_  
\_\_\_\_\_  
City, State, Zip: \_\_\_\_\_  
Phone: \_\_\_\_\_  
Fax: \_\_\_\_\_  
E-mail: \_\_\_\_\_

- Attending Seminar, Friday, November 2<sup>nd</sup>
- Request scholarship for travel and lodging to attend the Seminar (awarded on first-come-first-served basis. Payments will be made by mail after the conference)  
Amount requested – up to \$300 (there will be no reimbursement without receipts):  
\_\_\_\_\_

Special dietary needs: \_\_\_\_\_

The seminar is at the Holiday Inn Philadelphia International Airport. If you need lodging for November 1<sup>st</sup>, their number is (610) 521-2400. There are many other hotels in the area. The most MARHGN can reimburse for lodging in the Philadelphia area is \$138.

The NYMAC Medical Home Work Group will meet on Saturday, November 3<sup>rd</sup>. If you are attending the Seminar and would like to join the work group and attend the meeting (there are a limited number of spaces remaining), please check the box below. We will let you know if we can accommodate you.

- Attending Work Group meeting, Saturday, November 3<sup>rd</sup>
- Lodging for Friday, November 2<sup>nd</sup>.