

Current Core Activities

- ★ Collaborate with consumer groups in the region to integrate their goals with NYMAC's.
- ★ Maintain the NYMAC website by posting:
 - ★ Information on current activities including work group activities
 - ★ Products developed by NYMAC and its partners
 - ★ A Resource Directory that includes information on specialty care centers, state newborn screening programs, state Maternal and Child Health Block Grant contacts, and patient and family support and advocacy groups
 - ★ Links to the other six regions, the National Coordinating Center and other websites
- ★ Assist with the expansion and standardization of the state newborn screening programs by facilitating training of MS/MS laboratory personnel, linkages with metabolic specialists in the region
- ★ Monitor continuity-of-operations planning within the region for newborn screening and clinical activities in case of emergencies
- ★ Work with the National Coordinating Council (NCC) and the other six regions on projects of regional and national importance
- ★ Develop collaborations with medical and public health associations to further the collective visions of all.

Delaware
District of Columbia
Maryland
New Jersey
New York
Pennsylvania
Virginia
West Virginia

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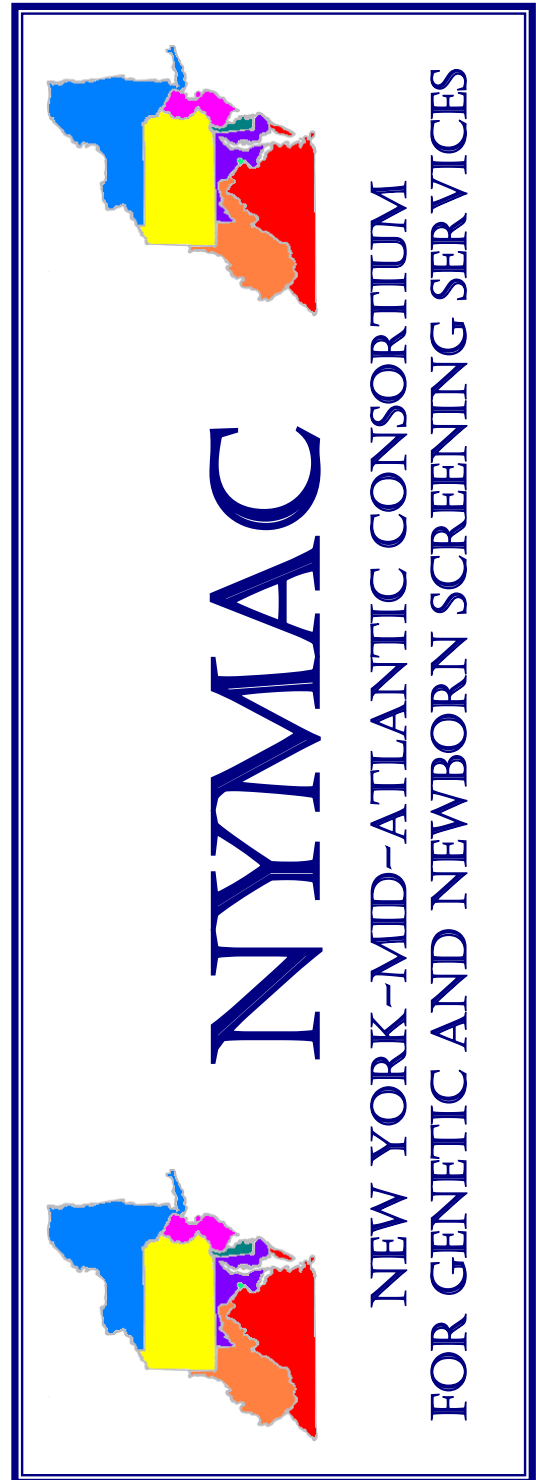
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NYMAC is always seeking dedicated individuals with an interest in genetics, newborn screening and/or public health who are willing to contribute time and effort towards accomplishing its goal and objectives. Please contact us if you are interested in working with us.

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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. This should be provided in the context of a medical home that provides accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-effective care.

The Executive Committee includes **Michele Caggana**, *Project Director*, **Joann N. Bodurtha**, *Co-Project Director* and **Katharine B. Harris**, *Project Manager*. This committee is ultimately responsible to HRSA for all activities of the collaborative.

The Advisory Council provides oversight to the project. Its members are asked to review the project activities on a regular basis and provide feedback. The Advisory Council incorporates expertise from state newborn screening, Title V (Maternal and Child Health) and Children with Special Health Care Needs programs, clinical genetic service, specialty care service, and teratogen service providers, clinical genetic testing laboratories, clinical genetics and genetic counseling training programs, medical insurers, primary medical care providers, professional organizations, consumer organizations and individual patients and their families. At least three people from each state serve on the Advisory Council, selected for their expertise in this range of services.

The Project Staff, **Bonnie L. Fredrick** (*Project Coordinator*), and a Soon-to-be-Hired Patient and Family Coordinator coordinate the workgroups, subcontracts and the day-to-day activities of NYMAC. **Susanna Ginsburg** (*NYMAC Evaluation Consultant*) works with NYMAC staff and partners to enable evaluation of NYMAC activities

Subcontracts and consultant agreements are used to address the goals of NYMAC. Current projects include:

- **Integration of Specialty Care and Primary Care into a Medical Home** awarded to Albany Medical Center, Brookdale University Hospital and Medical Center and University of Maryland Medical Center.
- **Consumer Education and Outreach** Awarded to CARES Foundation, Genetic Alliance, Immune Deficiency Foundation, Hunter's Hope Foundation, Sickle Cell Association of New Jersey, and Sickle Cell Thalassemia Patients Network
- NYMAC worked with the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children in **Evaluation of Health Insurance Coverage for Medical Foods and Supplements for Children with Metabolic Disorders**. Consulting partners included Albany Medical Center, Children's Hospital of Pittsburgh, Mount Sinai Medical Center, Regional Medical Genetics Center, University of Maryland Medical Center, and University of Rochester-Strong Memorial Hospital.
- **Participation in the Inborn Errors of Metabolism Information Survey**. Consulting partners include Hackensack University Medical Center, University of Buffalo, University of Pittsburgh and University of Rochester.
- **Transition Programs for Young Adults with Special Health Care Needs**. Consulting partners include A.I. duPont Hospital for Children, Children's Center for Cancer and Blood Disorders of Northern Virginia and University of Maryland, Baltimore

Current and Future NYMAC Projects

Ensure Enhanced Health Care Proxies for Adults with Special Health Care Needs

Champion: **Donna Appell**

Early Intervention Needs for Children Diagnosed through Newborn Screening

Champion: **Louis Bartoshesky**

Community-based Newborn Screening Follow-up for Presumptive Positive Newborns

Champion: **Luba Djurdjinovic**

Enhancement and Maintenance of the NYMAC Website

Champion: **Bonnie Fredrick**

Genetic Education and Outreach to the Asian Communities

Champions: **Patricia Giardina, Rita Bellevue and Susan Brooks**

Emergency Preparedness Interest Group

Champion: **Katharine Harris**

Criteria Used to Diagnose Screen-Positive Newborns with Metabolic Disorders/Coverage for Testing by Health Insurance

Champion: **David Kronn**

Newborn Screening Diagnostic Guidelines – Maintenance and Education

Champion: **David Kronn**

Educational Toolkit for Childbirth Educators to Introduce NBS to Expectant Parents

Champion: **Deborah Rodriguez**

NYMAC Congenital Hypothyroidism Interest Group

Champion: **Robert Rapaport**

Emergency Information Cards for People with Special Health Care Needs

Champion: **Deborah Rodriguez**

Workshop and Seminar for Newborn Laboratory Screening for Severe Combined Immunodeficiency Disease and Lysosomal Storage Diseases

Champion: **Beth Vogel**

Use of Telemedicine to Enable Prompt Follow-up of Screen-Positive newborns in Rural Areas

Champion: **Jerry Vockley**