Disorder Resources

The following resources include information on clinical trials, disorder-specific information, studies, and research.

National Institutes of Health Genetic and Rare Diseases Information Center
www.rarediseases.info.nih.gov
- Disorder information
- Information guides

National Organization for Rare Disorders
www.rarediseases.org
- Overview for disorders
- Rare Disease Database
- Clinical trials and research studies

Baby's First Test
www.babysfirsttest.org
- Genetic specialists
- Disorder information

Genetic Alliance
www.geneticalliance.org
- Promise for Engaging Everyone Responsibly (PEER)
- Build registry for research

New England Consortium of Metabolic Programs
www.newenglandconsortium.org
- Disorder information
- Nutrition resources

Newborn Screening Program
Wadsworth Center
New York State Department of Health
120 New Scotland Avenue
Albany, NY 12208
nbsinfo@health.ny.gov
(518) 473-7552
www.wadsworth.org/LTFU

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U1W42317. 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 families navigating an Inherited Metabolic Disorder (IMD) diagnosis.
Financial Resources

Medicaid Health Homes
www.health.ny.gov/health_care/medicaid/program
- Connect to health care providers
- Connect to needed medications
- Help with housing
- Social services (food, benefits, and transportation)
- Connect to community programs

NY Connects
www.nyconnects.ny.gov/home
- Free connection tools for long-term services
- Assistance with medical and nonmedical transportation, home care, and meals

Parent to Parent New York State
www.ptopnys.org
- Health insurance resources
- Tax-advantaged savings accounts for individuals with disabilities and their families
- Grants

Baby’s First Test
www.babysfirsttest.org
- Insurance and planning
- Financial assistance groups
- Policy insights on health insurance

Modivcare
www.modivcare.com
- Nonemergency medical transportation
- Medicaid & Medicare accepted

Social Support

New York Mid-Atlantic Caribbean Regional Genetics Network
www.nymacgenetics.org
- Parent experience portal
- General resources for patients and families

Parent to Parent New York State
www.ptopnys.org
- Connect one-to-one with a parent/caregiver of an individual with the same or similar disability or special health care needs

Baby’s First Test
www.babysfirsttest.org
- List of organizations
- Search engines to find support groups

National Organization for Rare Disorders
www.rarediseases.org
- Webinars, fact sheets, and infographics for individuals with rare diseases

New England Consortium of Metabolic Programs
www.newenglandconsortium.org
- Toolkits for transitioning to adulthood

Education

New York State Department of Education
www.nysed.gov/special-education/individualized-education-program-iep
- New York State IEP process
- Definitions, standards, and steps

New York City Department of Education
www.schools.nyc.gov/learning
- New York City IEP process
- Parent members

Parent to Parent New York State
www.ptopnys.org
- Links to special education resources
- Partners with specialists
- Department of Education

Center for Parent Information & Resources
www.parentcenterhub.org
- Parent centers
- Resources to participate in education and development
- Partnering with professionals and policymakers

Council for Exceptional Children
www.exceptionalchildren.org
- Families and educational professionals shaping education
- Resources for families and changing education standards