

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

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Department
of Health

Wadsworth
Center

A path to resources.



For families navigating an Inherited Metabolic Disorder (IMD) diagnosis.

Financial Resources



The following resources include information on financial planning, health insurance, and transportation assistance.

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



The following resources include information on advocacy, connecting and sharing personal experience, and support groups.

New York Mid-Atlantic Caribbean Regional Genetics Network

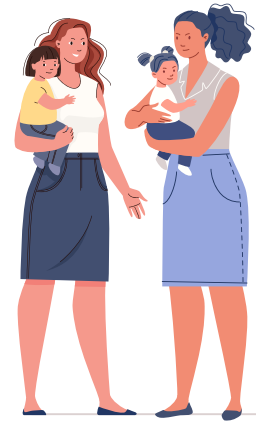
www.nymacgenetics.org

- 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



The following resources include information on Individualized Education Plans (IEP), school-related support, and special 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