

# Resources for Families of Children with Special Needs

Use the listings below to find information, products, services and support for children with special needs. You can also contact the Growing Up Healthy Hotline at (800) 522-5006 or your local health department.



## Programs

### Physically Handicapped Children's Program (PHCP) for Children with Special Health Care Needs

**Contact:** Growing Up Healthy Hotline at (800) 522-5006, or the PHCP coordinator at your local health department.

This program is available at many county health departments and is designed to ensure access to quality health care for chronically ill and disabled children. It provides funds for diagnostic services as well as a reimbursement to health care providers for treatment. Children between the ages of birth to 21 years of age that meet the county's financial and medical requirements qualify for assistance.

### NY State of Health: The Official Health Plan Marketplace

**Contact:** (855) 355-5777

Visit this website to shop, compare and enroll in a low-cost quality plan that is right for you. This is the only place where you can receive financial assistance based on income to help offset costs. The marketplace will determine if you qualify for Child Health Plus, Medicaid, Tax Credits or Cost Sharing reductions.

### Child Health Plus

**Contact:** (800) 698-4543

Child Health Plus is a health insurance plan for children under the age of 19 who are not eligible for Medicaid and have limited or no health insurance. Some of the services covered by Child Health Plus are well-child care, immunizations, physical exams, physical therapy, x-ray and lab tests, and emergency room care.

### Early Intervention Program

**Contact:** Growing Up Healthy Hotline at (800) 522-5006 or your local health department

The Early Intervention Program is designed to enhance the development of infants and toddlers with disabilities and/or developmental delays and the capacity to meet their special needs. Services include screening and evaluation, service coordination, family training, counseling, home visits, parent support groups, vision services, physical therapy, occupational therapy, nutrition services, nursing services, psychological therapy, social work services, special instruction, transportation and assistive technology devices and services. Any child under the age of three who has a developmental delay or a diagnosed physical or mental condition that meets New York State criteria is eligible. Services are provided at no out-of-pocket cost to families and are determined on an individual basis.

### New York State Genetics Services Program

**Contact:** (518) 474-7148

The New York State Genetics Services Program administers contracts that fund comprehensive and non-categorical genetics centers that provide genetic counseling, diagnosis and treatment services statewide. Its goal is to ensure that genetic services are available throughout New York State, and that under-served areas have access to services.

### March of Dimes

**Contact:** (888) 663-4637 or your local March of Dimes chapter listed in the white pages or online at [modimes.org](http://modimes.org)

March of Dimes is a not-for-profit organization dedicated to improving the health of babies by preventing birth defects and infant mortality.

It provides information on maternal and infant health. This information ranges from pre-pregnancy planning and birth defects to genetic counseling.

### **Parent to Parent of New York State**

**Contact:** (800) 305-8817 or online at [parenttoparentnys.org](http://parenttoparentnys.org)

Parent to Parent of New York State provides emotional support and information for parents of children with disabilities or special health care needs. Some services include connecting families of children with disabilities to other families, offering information on community and statewide resources, and providing trainings on topics related to accessing services provided by New York State's Office for People with Developmental Disabilities, Medicaid Service Coordination, Health Care Notebooks and Transition to Adult Health Care.

### **Family Support Services**

**Contact:** (866) 946-9733 / TTY: (866) 933-4889 or email [people.first@opwdd.ny.gov](mailto:people.first@opwdd.ny.gov). For information on eligibility please contact your Regional Office: [opwdd.ny.gov/node/1022](http://opwdd.ny.gov/node/1022)

The Office for People With Developmental Disabilities (OPWDD) offers services to assist individuals with developmental disabilities and their families including respite care, recreational activities, employment support, family reimbursement, case management, financial and life planning assistance, infant therapies and nutrition, information and outreach, and transportation. The program funds services through not-for-profit agencies in the community and through the Developmental Disabilities Regional Offices (DDROs).

## **Internet Resources**

These websites provide resources for parents of children with special health care needs, including information and links to support and advocacy groups.

### **NYS Department of Health**

[health.ny.gov](http://health.ny.gov)

### **The Magic Foundation**

[magicfoundation.org](http://magicfoundation.org)

### **MUMS National Parent to Parent**

[netnet.net/mums](http://netnet.net/mums)

### **Family Voices**

[familyvoices.org](http://familyvoices.org)

### **Disability Information and Resources**

[makoa.org](http://makoa.org)

### **Alliance of Genetic Support Groups**

[geneticalliance.org](http://geneticalliance.org)

### **The Healthfinder**

[healthfinder.gov](http://healthfinder.gov)

### **Compassionate Friends**

[compassionatefriends.org](http://compassionatefriends.org)

### **Brave Kids**

[bravekids.org](http://bravekids.org)

### **Kids with Heart National Association for Children's Heart Disorders, Inc.**

[kidswithheart.org](http://kidswithheart.org)

### **Mended Little Hearts**

[mendedlittlehearts.org](http://mendedlittlehearts.org)

### **Oral Clefts and Craniofacial Deformities**

[cleftline.org](http://cleftline.org); [cleft.org](http://cleft.org)

### **Spina Bifida Association of America**

[sbaa.org](http://sbaa.org)

### **Anencephaly Information**

[anencephaly.info](http://anencephaly.info)

### **Chromosome 18 Abnormalities**

[chromosome18.org](http://chromosome18.org)

### **National Organization of Rare Disorders**

[rarediseases.org](http://rarediseases.org)

### **Our-Kids**

[our-kids.org](http://our-kids.org)

### **NYS Department of Health Resource Directory for Children and Young Adults with Special Health Care Needs**

[health.ny.gov/publications/0548.pdf](http://health.ny.gov/publications/0548.pdf)

### **Contact Local Health Departments**

<http://www.health.ny.gov/contact/>