



FINDING A CURE FOR EPILEPSY & SEIZURES

# Pediatric Epilepsy Resource Handbook

Fourth Edition

Revised December 2008

**Faces – Finding A Cure for Epilepsy and Seizures**  
223 East 34<sup>th</sup> Street  
New York, NY 10016  
(646) 558-0900  
[www.nyufaces.org](http://www.nyufaces.org)

### **DISCLAIMERS:**

All therapies and medical professionals listed in this guide have been provided by parents, adults and caregivers affected by epilepsy.

The information provided in this document is for information purposes only. Any medical decisions are solely the responsibility of the treating physician and patient. The information provided in this guide is not endorsed by **faces**, the NYU Comprehensive Epilepsy Center or NYU Langone Medical Center personnel. This guide does not represent the NYU Comprehensive Epilepsy Center in any way; neither does **faces** or the NYU Comprehensive Epilepsy Center give endorsement of any product or person.

If you are interested in submitting an entry for the next alternative therapies guide, please contact the **faces** office at (646) 558-0900 or email [facesinfo@nyumc.org](mailto:facesinfo@nyumc.org)

## National Epilepsy Resources

### **American Epilepsy Society**

342 North Main Street  
West Hartford, CT 06117  
Phone (860) 586-7505  
Email [info@aesnet.org](mailto:info@aesnet.org)  
[www.aesnet.org](http://www.aesnet.org)

### **Epilepsy Foundation**

8503 LaSalle Road  
Towson, MD 21286  
Phone (410) 828-7700 or (800) 332-1000  
[www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

A national organization that serves people affected by seizures through research, education, advocacy and services provided at over 60 affiliates nation-wide.

### **[www.Epilepsy.com](http://www.Epilepsy.com)**

[Epilepsy.com](http://www.Epilepsy.com) is an online resource provided by The Epilepsy Project. Their mission is to inform and empower two groups of patients and their families: those facing newly diagnosed epilepsy, and those struggling with epilepsy that has resisted the usual treatments.

### **Parents Against Childhood Epilepsy, Inc. (PACE)**

7 East 85th Street, Suite A3  
New York, NY 10028  
Phone (212) 665-PACE  
[www.paceusa.org](http://www.paceusa.org)

Formed in 1996 by a group of parents in response to their experiences in caring for the physical, social, educational, developmental and emotional needs of their children who suffer from seizures. PACE funding supports medical research into epilepsy and seizure disorders

and provides resources and information to support families with similar needs. 85 cents of every dollar PACE raises goes directly to research or support. To join PACE's email-based information resource for parents, send an email to [epilepsytalk@aol.com](mailto:epilepsytalk@aol.com).

## New York

### **Chrissy and Friends, Inc.**

62 Otis Avenue

Staten Island, NY 10306

Phone (718) 987-0940

Contact: RoseAnne DeRenzo

[www.chrissyandfriends.org](http://www.chrissyandfriends.org)

Chrissy and Friends offers free tutoring and an after-school recreation program for children and teens. A parent support group meets at the same time as the recreation program. Teen/adult bowling meets one night a month. Both children and adult groups go on trips. The mission of Chrissy and Friends is to offer support, recreation, education and most importantly a place to socialize and have fun for those living with epilepsy.

### **Epilepsy Coalition of New York State, Inc. (ECNYS)**

111 Washington Avenue

Albany, NY 12210

Phone (518) 434-4360

Fax (518) 434-4542

[www.epilepsyny.org](http://www.epilepsyny.org)

The ECNYS was organized to promote the awareness of epilepsy and its consequences to public and private sectors in N.Y. State and to improve the epilepsy service system throughout N.Y.

### **Epilepsy Foundation of Long Island, Inc. (EFLI)**

506 Stewart Avenue

Garden City, NY 11530

Phone (516) 739-7733

[www.efli.org](http://www.efli.org)

EFLI provides education, counseling, and residential care to Long Island residents with epilepsy and related conditions. Services include:

individual, family, and group counseling; vocational counseling; neurological assessment and diagnostic center; psychiatric consultations and psychological evaluations; relationship counseling; parent, sibling and spouse discussion groups; liaison and referral assistance to community agencies and local hospitals; Day Treatment and Day Habilitation; and stress reduction techniques. The Seizure Smart Program, Kids on the Block, and other advocacy programs strive to educate schools, students, and the community at large about epilepsy.

### **Epilepsy Foundation of New York City (EFNYC)**

305 Seventh Avenue, Suite 1202 New York, NY 10001 Phone (212) 633-2930 Fax (212) 633-2991 [www.epilepsyinstitute.org](http://www.epilepsyinstitute.org)

EFNYC helps individuals and families affected by epilepsy achieve their highest level of physical, social, and emotional wellbeing. We offer a variety of programs & services including counseling, education seminars on seizures and first aid, special fund raising events and the Adventurer's Club. The Adventurer's Club is a recreational program for children with epilepsy and their families. It allows kids to live beyond their limits and try new activities while socializing with other kids with epilepsy. Previous adventures have included indoor-rock climbing, trips to museums and zoos, and an African dance and drumming workshop.

### **Epilepsy Foundation of Northeastern New York, Inc.**

3 Washington Square Albany, NY 12205 Phone (518) 456-7501 or Toll Free (800) 894-3223 Fax (518) 452-1282

[www.epilepsyfoundation.org/efneny](http://www.epilepsyfoundation.org/efneny)

The Epilepsy Foundation of Northeastern New York, Inc, an independent affiliate of the national Epilepsy Foundation, is a non-profit organization whose mission is to provide education and advocacy services for people of all ages affected by epilepsy/seizure disorders and their loved ones. For more than 20 years, our information and support services have helped thousands of New Yorkers of all ages with epilepsy and other neurological impairments feel more comfortable about themselves and the way others see them. Our wide variety of programs, which are tailored to children, adults and their families, include school education programs, support groups, counseling, service coordination, and professional in-service training. Programs are

available to members and non-members of the Foundation. We serve residents in 19 counties including: Albany, Clinton, Columbia, Essex, Franklin, Fulton, Greene, Hamilton, Herkimer, Jefferson, Lewis, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Street Lawrence, Warren and Washington.

### **Epilepsy Foundation of Rochester-Syracuse-Binghamton Rochester Office**

1650 South Avenue, Suite 300  
Rochester, NY 14620  
Phone (585) 442-4430, ext. 2702  
Fax (585) 442-6305  
Theresa King, Community Educator  
Email [t\\_king@epilepsy-uny.org](mailto:t_king@epilepsy-uny.org)

### **Syracuse Office**

800 South Wilbur Avenue  
Syracuse, NY 13204  
Phone (315) 473-6974 or Toll Free (877) 214-7715  
Fax (315) 473-6996  
[www.epilepsyuny.org](http://www.epilepsyuny.org)

### **Binghamton Office**

3 Osteningo Street, 2nd Floor  
Binghamton, NY 13903  
Phone (607) 723-4203  
Fax (607) 771-8723  
[www.epilepsy-uny.org](http://www.epilepsy-uny.org)

The Epilepsy Foundation of Rochester-Syracuse-Binghamton helps individuals and families of all cultures affected by epilepsy and related neurological impairments understand, manage, and cope with their disorders by providing education, advocacy and services. Education includes public education for schools, civic groups and corporations and is designed to teach the public how to identify and respond to seizures. Some of our other services include: Residential Services, Family Support Services, Counseling and Support Services, Case Management Services, Employment Programs, and Camp Eagr, a residential summer camp for boys and girls, ages 8 to 15, with epilepsy, regardless of seizure control.

### **Epilepsy Society of Southern New York, Inc. (ESSNY)**

One Blue Plaza Suite 340,

Box 1745

Pearl River, NY 10965

Phone (845) 627-0627, Toll-free (800) 640-0371

Fax (845) 627-0629

[www.essny.com](http://www.essny.com)

ESSNY provides comprehensive services to individuals with epilepsy and other developmental disabilities such as mental retardation, cerebral palsy, autism, and traumatic brain injury in Westchester, Putnam, Rockland, Dutchess, Ulster, Sullivan and Orange counties. Our Service Coordination Department offers Medicaid Service Coordination, Home and Community Based Waiver services, Traumatic Brain Injury Waiver services and Non-Medicaid Service Coordination through our Family Support Program. Integrated Supported and Competitive Employment programs include job coaching and follow along services. Residential Habilitation services are provided in the home. Complete Education services are also provided.

### **The Epilepsy Institute**

257 Park Avenue South, Suite 302

New York, NY 10010

Phone (212) 677-8550

[www.epilepsyinstitute.org](http://www.epilepsyinstitute.org)

Since 1967, New York City residents with epilepsy and their families have benefited from the comprehensive social and educational services offered by The Epilepsy Institute. Its five metropolitan office sites are collectively staffed by licensed professionals from the medical, social work, vocational counseling, and psychological professions. Quality services include New York City's only specialized supported employment, state certified counseling clinic and day habilitation programs exclusively serving persons with epilepsy. Other programs include service coordination, information and referral services, educational services, stress management, summer camp, and a weekend socialization program. All programs are free or low cost, and no one has ever been turned away based on inability to pay.

### **Faces - Finding A Cure for Epilepsy & Seizures**

NYU Comprehensive Epilepsy Center/NYU Tuberous Sclerosis Center

223 East 34<sup>th</sup> Street  
New York, NY 10016  
Phone (646) 558-0900  
[www.nyufaces.org](http://www.nyufaces.org)

**Faces** promotes research into neuroprosthesis, magnetic stimulation, Biofeedback, and new surgical procedures. **Faces** is also a member of the Partnership for Pediatric Epilepsy Research and supports the Epilepsy Phenome/Genome Project. Other programs include free educational conferences, social events for children and teens, summer camp scholarships, support groups for parents, two charity apartments for parents of children undergoing epilepsy treatment, a respite care program, a social group for young professionals, and community education for police officers, teachers and more. **Faces** supports the NYU Tuberous Sclerosis Center.

### **Resources for Children with Special Needs**

116 East 16th Street, 5th Floor  
New York, NY 10003  
Phone (212) 677-4650  
Email [info@resourcesnyc.org](mailto:info@resourcesnyc.org)  
[www.resourcesnyc.org](http://www.resourcesnyc.org)

Resources for Children with Special Needs is a comprehensive, independent, not-for profit information, referral, advocacy, training and support center for New York City parents and professionals looking for all types of programs and services for children from birth to 21 with learning, developmental, emotional, or physical disabilities. Resources is designated by the US Department of Education as one of a national network of more than 100 parent training and information centers.

## **New Jersey**

### **Epilepsy Foundation of New Jersey (EFNJ)**

429 River View Plaza  
Trenton, NJ 08611  
Phone (609) 392-4900  
Fax (609) 392-5621  
[www.efnj.com](http://www.efnj.com)

EFNJ, an affiliate of the national Epilepsy Foundation, is a statewide, non-profit charitable agency dedicated to the welfare of the over 125,000 New Jersey residents with epilepsy and their families. EFNJ's purpose is to provide services and support to enable people with epilepsy to realize their full potential and to optimize their participation in society. Since 1970, EFNJ has provided a wide variety of programs and services at no charge to anyone with epilepsy and/or developmental disabilities, their families and interested relatives, neighbors, friends, and community members.

### **Family Support Center of New Jersey**

2516 Highway 35

North Manasquan, NJ 08736

Phone (732) 528-8080

[www.familysupportnj.com](http://www.familysupportnj.com)

The Family Support Center is a clearinghouse of up-to-date information on national, state, and local family support programs, services and disabilities. The Center offers a "One-Stop Shopping" approach to individuals seeking information on disabilities and services by providing them with easy access to a comprehensive array of services.

## **Connecticut**

### **Epilepsy Foundation of Connecticut (EFCT)**

386 Main Street

Middletown, CT 06457

Phone (860) 346-1924

Fax (860) 346-1928

[www.epilepsyct.net](http://www.epilepsyct.net)

EFCT, an independent affiliate of the national Epilepsy Foundation, is dedicated to helping people with epilepsy and their families understand, manage, and cope successfully with the condition, to further public understanding, reduce stigma, and increase acceptance of people with epilepsy. This is accomplished through programs and services including: Public and Professional Information & Education, a Parent and Family Telephone Network, Support Groups, and a Summer Camp for Children and Teens with Epilepsy. Our services are provided at no

cost to people with epilepsy, their families and the public throughout Connecticut.

### **The Special Education Resource Center (SERC)**

25 Industrial Park Road  
Middletown, CT 06457-1520  
Phone (860) 632-1485  
[www.ctserc.org](http://www.ctserc.org)

This is the essential first step for a parent of a child in special education to become an informed advocate. The center is affiliated with the Connecticut Department of Education. Parents should call and request the Resource Package for Parents of Children with Special Needs. This package is free and includes the Connecticut Special Education statutes and commentary on them plus other materials. Parents may also join the SERC. Membership is free and benefits include receiving a newsletter with information about educational seminars and materials available in their library.

### **Connecticut Parent Advocacy Center (CPAC)**

338 Main Street  
Niantic, CT 06357  
Phone (800) 445-CPAC  
[www.cpacinc.org](http://www.cpacinc.org)

CPAC informs parents about their children's rights under the special education laws in Connecticut. Parent advisors answer questions and provide assistance and information by phone for free.

## Summer Camps (Tri-State)

### **Father Drumgoole-Connelly Summer Day Camp at Mt. Loretto**

Staten Island, NY Phone (718) 317-2255

Contact: Brian Landano

This camp is designed for children ages 5-12. There are four sessions lasting two weeks long and a final session that lasts for one week. The sessions are Monday-Friday. There are also 3-day and 2-day summerlong sessions. The 3-day sessions meet on Mondays, Wednesdays and Fridays. The 2-day sessions meet on Tuesdays and Thursdays. All sessions are from 8:30am-3:30pm. The camp features a wheelchair accessible pool, arts and crafts, music, sports, drama, nature and outdoor play. The camp counselors receive seizure first aid training and a registered nurse is on duty at all times.

### **The Epilepsy Foundation of New Jersey's Camp Nova**

Blairstown, NJ

Contact: Helen Sherman

Phone (856) 858-5900

Email [hsherman@efnj.com](mailto:hsherman@efnj.com)

[www.efnj.com/programs/campnova.shtml](http://www.efnj.com/programs/campnova.shtml)

Camp NOVA is a one-week overnight camp experience for individuals with epilepsy and developmental disabilities. It is dedicated to the overall growth and well being of children and young adults ages 8 to 25. The camp provides swimming, boating, campfires, outdoor sports, beach volleyball, fishing, nature walks, and more. There is an on-call neurologist and an on-site nurse. All counselors receive training in first aid.

### **The Epilepsy Foundation of Connecticut's Easter Seals Camp**

Hebron, CT

Contact: Patrick Danis

Phone (800) 899-EPIL

[www.epilepsyct.net](http://www.epilepsyct.net)

EFCT's one-week overnight camp is for kids ages 6-18. The facility includes a health center, auditorium, indoor-heated pool, greenhouse, Arts & Crafts Center, a Nature Center, and a Challenge & Group Initiative course. All counselors receive specialized training in seizure recognition and first aid and a licensed nurse is in residence at all times. The camper to counselor ratio is 3 to 1.

### **The Epilepsy Foundation Western/Central Pennsylvania's Camp Frog**

North Springfield, PA

Contact: Kate Wilson Phone (800) 361-5885

[www.efwp.org/programs/programs\\_08.shtml](http://www.efwp.org/programs/programs_08.shtml)

The Epilepsy Foundation Western/Central Pennsylvania sponsors a week-long, overnight summer camping program called Camp Frog, located on the shores of Lake Erie. Camp Frog allows kids with epilepsy/seizure disorders to be integrated into a typical camping experience with hundreds of other children. The overnight program is available to boys and girls with epilepsy/seizure disorders from grades 4 to 11. Campers enjoy a host of activities, such as archery, horseback riding, a climbing tower, sand volleyball, indoor-outdoor hockey, soccer, miles of hiking trails, boating, fishing, swimming, sailing, water-skiing, and canoeing. Waterfronts are supervised by certified lifeguards. All camp staff members receive specialized training in seizure recognition and first-aid training and a licensed pediatric neurologist and a registered nurse are on-site. Scholarships and financial assistance are available to eligible campers. Preference is given to residents of Western and Central PA.

### **Camp Loyaltown**

Nassau County

Contact: Paul Cullen

Phone (516) 293-1111

[www.ahrc.org/camployaltown.0.html](http://www.ahrc.org/camployaltown.0.html)

Camp Loyaltown is a private, nonprofit, summer residential, respite camp which cares for children as young as 4 years old through adults in

their 80ís who have developmental and other disabilities. Camper's functional levels range from mildly developmentally disabled through severely disabled. The camp is situated on 235 wooded acres in the northern Catskill Mountains in Hunter, NY offering campers a complete program of recreation. These programs include swimming, boating, nature, arts & crafts, ceramics, fabric arts, dance, drama, woodworking, athletics, music and cooking. Campers are grouped by age and abilities and staff are assigned according to the needs of each individual.

### **The Epilepsy Foundation Rochester/Syracuse/Binghamton's Camp EAGR**

Warsaw, NY

Contact: Mike Radell

Phone (585) 442-4430

[www.epilepsyfoundation.org/local/rochester/campeagr.cfm](http://www.epilepsyfoundation.org/local/rochester/campeagr.cfm)

Camp EAGR is a one-week overnight camp for kids with epilepsy ages 8 to 15, who are ambulatory and capable of managing their own personal needs. EAGR is held at the YMCA of Greater Buffalo's Camp Weona.

Activities include: swimming, canoeing, fishing, horseback riding, arts and crafts, organized sports, hiking, epilepsy education and campfire sing-a-longs. Camper to staff ratio is 3:1. Camp counselors are certified in seizure first aid. There is an on-site neurologist, and two on-site nurses for distribution of medication and basic first aid.

## **Travel Assistance for Families Seeking Medical Treatment**

### **American Airlines “Miles for Kids in Need”**

Contact: Program Administration

Phone (817) 963-8158 Fax (817) 931-6890

[www.americanairlines.com](http://www.americanairlines.com)

Miles for Kids in Need provides air transportation for children needing medical treatment. Must be a dependant child under 19 years of age, and the child’s family must be recommended by a social worker at a medical institution, a charitable organization, or a church.

### **The National Epilepsy Foundation J. Kiffin Penry Travel Assistance Program**

Phone (800) EFA-1000

[www.efa.org](http://www.efa.org)

When people with seizures need specialized care, it may not be available in the local area. Travel expenses for individuals and families may sometimes be a barrier to such care. The Epilepsy Foundation offers a limited number of travel assistance grants, up to \$1,500 each (over a two-year period), for people who must travel for specialized epilepsy care or testing.

### **Ronald McDonald House (New York City)**

405 East 73rd Street

New York, NY 10021

Phone (212) 639-0100

Ronald McDonald House gives priority to patients affected by cancer, but sometimes makes housing available to other patients. Located on East 73rd Street between First Avenue and York. Requires a \$30 deposit and costs approximately \$20 a night.

## Clinical Trials

## Special Education Information

For a listing of clinical trials for epilepsy, go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and do a search on “epilepsy.”

### **Families and Advocates Partnership for Education (FAPE)**

PACER Center 8161 Normandale Boulevard

Minneapolis, MN 55437

Phone (952) 838-9000 TTY (952) 838-0190

Fax (952) 838-0199

Email [fape@fape.org](mailto:fape@fape.org)

[www.fape.org](http://www.fape.org)

FAPE aims to improve the educational outcomes for children with disabilities. It links families, advocates, and self-advocates to communicate the new focus of the Individuals with Disabilities Education Act (IDEA).

### **Learning Disabilities Online**

[www.ldonline.org](http://www.ldonline.org)

This learning disabilities website for parents and teachers has great links to information about learning disabilities.

### **Negotiating the Special Education Maze: A Guide for Parents & Teachers, 3rd edition, by Winifred Anderson**

This book is an introduction to special education law and the process of getting services for your child.

### **Sensory Integration Network**

[www.sinetwork.org/home/index.html](http://www.sinetwork.org/home/index.html)

A website for parents, teachers, and therapists on sensory integration problems. Contains useful pamphlets that can be downloaded to explain Dysfunctional Sensory Integration to teachers.

### **Wrightslaw**

[www.wrightslaw.com](http://www.wrightslaw.com)

A comprehensive website dedicated to special education, including what rights children and parents have, and how parents can advocate for their children. Both IEPs and Section 504 accommodations are discussed. Any question or concern a parent could have about getting needed services for their child is covered. Most content is written specifically for the site by the Wrights, an attorney and a psychologist, both experts in special education.

## Special Schools

### **The Cooke Center for Learning and Development**

475 Riverside Drive, Suite 730 (administrative offices)

New York, NY 10115

Phone (212) 280-4473

Fax (212) 280-4477

[www.cookecenter.org](http://www.cookecenter.org)

Email [info@cookecenter.org](mailto:info@cookecenter.org)

Started in 1987, the Cooke Center for Learning and Development offers high quality, inclusive educational opportunities for children with a range of developmental disabilities. Our students, ages 3-21, are educated through our preschool, elementary and high school programs. Our full-time school program services 120 students in 9 partner school sites. We also work with several thousand more students through our School Wide Intervention Program. They have a range of disabilities including Down Syndrome, Neurological impairment, Fragile X Syndrome, epilepsy and physical disabilities. Cooke prides itself in its professional development and training programs that now reach out to educators across the country. Our staff is comfortable dealing with students who have seizures and each year train personnel to deal with these types of disorders and give emergency medical attention when needed.

### **Churchill School**

301 East 29th Street

New York, NY 10016

Director of Admissions: Ms. Wendy Fedirco

Phone (212) 722-0610  
Fax (212) 722-1387  
www.churchillschool.com  
\*High functioning learning disabled

### **The Demonstration Program at Montclair University**

47 Clove Road  
Upper Montclair, NJ 07043  
Director: Antoinette Spiotta Phone (973) 655-4357 ext. 7177  
Fax (973) 655-5155

### **Eagle Hill School**

45 Glenville Road  
Greenwich, CT 06831  
Director: Mark Griffin, PhD  
Phone (203) 622-9240  
Fax (203) 622-0914  
Email [info@eaglehill.org](mailto:info@eaglehill.org)  
www.eaglehillschool.org  
\*High functioning learning disabled

### **Ferncliff Manor**

1154 Saw Mill River  
Road Yonkers, NY 10710  
Director: Steven Madey  
Phone (914) 968-4854  
Fax (914) 968-4857  
\*Mild-severe mental retardation

### **The Forum School**

107 Wycoff Avenue  
Waldwick, NJ 07463  
Director: Steven Krapes  
Phone (201) 444-5882  
Fax (201) 444-4003  
www.theforumschool.com

### **The Gateway School**

236 Second Avenue

New York, NY 10003  
Director: Robert B. Cunningham  
Phone (212) 777-5966  
Fax (212) 777-5794  
Email: [info@gateways.org](mailto:info@gateways.org)  
[www.gatewayschool.org](http://www.gatewayschool.org)  
\*Ages 5-10

### **The Gillen Brewer School**

1190 Park Avenue  
New York, NY 10128  
Administrative Director: Laurie DeBos  
Phone (212) 831-3667  
Fax (212) 831-5254  
\*Up to age 8

### **Hawthorne Country Day School**

5 Bradhurst Avenue  
Hawthorne, NY 10532 Director: Christopher McDonough, PhD, BCBA  
Phone (914) 592-8526 Fax (914) 592-3227  
2nd location:  
Manhattan Campus  
468 West 143rd Street  
New York, NY 10031  
Phone (212) 281-6531  
Fax (212) 281-6723  
[www.hawthornecountryday.org](http://www.hawthornecountryday.org)  
\*Autism

### **The Midland School**

94 Readington Road  
North Branch, NJ 08876  
Director: Phillip Gartlan  
Phone (908) 722-8222  
\*Ages 5-21

### **Mt. Pleasant Blythedale Children's School**

95 Bradhurst Avenue  
Valhalla, NY 10595  
Principal: Lisa O'Shea  
Phone (914) 347-1800 ext. 201  
Fax (914) 347-2307  
Email: [loshea@blythedale.org](mailto:loshea@blythedale.org)  
[www.blythedale.org](http://www.blythedale.org)

### **Parkside School**

48 West 74th Street  
New York, NY 10023  
Administrative Director: Albina Miller  
Phone (212) 721-8888  
Fax (212) 721-1547  
[www.parksideschool.org](http://www.parksideschool.org)  
\*Age 5-10

### **The Stephen Gaynor School**

198 West 90th Street  
New York, NY 10024  
Director: Dr. Miriam Michael  
Phone (212) 787-7070  
Fax (212) 787-3312  
[www.stephengaynor.com](http://www.stephengaynor.com)

### **The Smith School**

131 West 86th Street  
New York, NY 10024  
Director: Karen Smith  
Phone (212) 879-6354  
Fax (212) 879-0962  
Email: [edu@smithschool.net](mailto:edu@smithschool.net)  
[www.SmithSchool.net](http://www.SmithSchool.net)

### **Westchester School for Special Children**

45 Park Avenue

Yonkers, NY 10703  
Director: Donald Scampoli  
Phone (914) 376-4300  
Fax (914) 965-7059  
\*Mild-severe mental retardation

### Education Consultants

**Patricia Sokolow**  
407 3rd Avenue  
Waretown, NJ 08758  
Phone (609) 698-5275

### Finding an Epilepsy Specialist

New York City is home to several Comprehensive Epilepsy Centers, where you will find some of the best epilepsy specialists in the world. You can locate top epileptologists, neuropsychologists, and more through the American Epilepsy Society and the National Association of Epilepsy Centers.

#### **American Epilepsy Society (AES)**

342 N. Main Street  
West Hartford, CT 06117  
Phone (860) 586-7505  
<http://www.aesnet.org>

The AES web site features a searchable member directory where you can find epilepsy specialists near you.

#### **National Association of Epilepsy Centers (NAEC)**

5775 Wayzata Blvd.  
Minneapolis, MN 55415  
(952) 525-4526

<http://www.naecepilepsy.org>

The NAEC is a non-profit (501 c 6-trade association) whose members include more than 50 specialized epilepsy centers.

### **Prescription Drug Patient Assistance Programs**

For an excellent chart on pharmaceutical companies that have Prescription Assistance Programs for epilepsy medications, please see *Epilepsy: Patient and Family Guide*, 2nd edition, pages 135-138, by Orrin Devinsky, MD, F.A. Davis Company, 2002. Proceeds from the book (which can be purchased new or used at [www.amazon.com](http://www.amazon.com)) go to faces and the National Epilepsy Foundation. You may also email [facescoordinator@yahoo.com](mailto:facescoordinator@yahoo.com) to receive a copy of the chart via fax or mail.

#### **Pharmaceutical Research and Manufacturers of America (PhRMA)**

1100 15th Street  
NW Washington, DC 2005

PhRMA has information on prescription drug patient assistance programs on their web site at [www.helpingpatients.org](http://www.helpingpatients.org).

### **Therapists Recommended by Parents of Children with Epilepsy**

# Applied Behavioral Analysis Therapists

## **Programs for Little Learners, LLC**

Executive Directors: Eileen Boothe, OT and Jennifer Strazzeri, OT

10 Wilsey Square, Suite 248

Ridgewood, NJ 07450

Phone (201) 251-3800

[www.programsforlittlelearners.com](http://www.programsforlittlelearners.com)

and

266 White Plains Rd., Suite 2A

Eastchester, NY 10709

Phone (914) 337-3026

## **Occupational Therapists**

## **Pediatric Potentials of West Essex, LLC**

Director: Laurie Kalb, OTR, BCP Patricia Faller, OT Grace Malone, OT

154 South Livingston Avenue, Suite 203-205

Livingston, NJ 07039

Phone (973) 535-5010

## **PowerPlay Pediatric Therapy Center, LLC**

Executive Director: Greg Sanlucchi, MS, OTR

32 Beach Road

Monmouth Beach, NJ 07750

Phone (201) 223-4949

PowerPlay Pediatric Therapy Center, LLC for pediatric therapy has occupational and physical therapists on staff and offers both school and clinic services. We have a newly renovated clinic with suspended equipment, a parent observation area and a vibrant, experienced staff who have devoted themselves to helping children with special needs. Greg Santucci also provides additional services in sensory integration and therapeutic listening. For more information, contact:

Executive Director: Gregory Santucci, MS, OTR Pediatric Occupational Therapist, certified in Sensory Integration, Phone (732) 571-2200 Email Gregorysantucci@aol.com

**Pediatric Occupational Therapy Services**

Director: Chaye Lamm-Warburg, MA, OTR, BCP  
1415 Queen Anne Road Teaneck, NJ 07666  
Phone (201) 837-9993  
Email potschaye@aol.com

**Jayne Lewin Rich, MPA, OTR/L**

39 West 14th Street, Suite 307  
New York, NY 10011  
Phone (212) 414-2777  
Email jaymerich.ot@earthlink.net

**Lori Rothman, OTR**

144 West 86th Street, #1B  
New York, NY 10024  
Phone (212) 595-7782  
Email LRoth123@aol.com

**Sara Schlussel, OTR**

100 Lybecker Street  
Englewood, NJ 07631  
Phone (201) 569-0767  
Email Mdotlevana@aol.com

**Physical Therapists**

**Susan Guzzardo, PT, DPT**

68-16 Eliot Avenue  
Middle Village, NY 11379  
Phone (212) 463-0400 x 647  
Email Sugu@earthlink.com

**Cindy Rosenbloom, PT**

6 Myrtle Avenue  
Demarest, NJ 07627  
Phone (201) 784-0842

**Hospital for Joint Diseases**

Jennifer Tisco 301 East 17th Street, 4th Floor  
New York, NY 10003  
Phone (212) 598-6248

**Helene Widman, PT**

Phone (917) 992-4065

**Speech Therapists**

Email KidPT64@aol.com

**Carmela Maio, MS, CCC-SLP, TSHH**

Speech and Language Pathologist  
15923 85th Street  
Howard Beach, NY 11414  
Phone (718) 641-6723

**Pam Davis**

Speech and Language Pathologist  
1060 5th Avenue  
New York, NY 10128  
Phone (212) 831-4344  
Email NUYKS@aol.com

**Rachel Fisch-Kaplan, MS, CCC-SLP**

New York Office:  
107 West 82nd Street, Suite 103

New York, NY 10024  
Phone (212) 712-2014  
Email Zoulicat2@aol.com  
New Jersey Office:  
48 Maple Street  
Summit, NJ 07901  
Phone (973) 420-6774

**TIKES (Therapeutic Intervention for Kids and Educational Support)**

Barbara Goldfarb-Portnoff, MA, CCC-SLP  
Speech and Language Pathologist  
206 Millburn Avenue, Suite 11A  
Millburn, NJ 07041  
Phone (973) 376-5888  
Email Tikes01@aol.com

**City Sounds of New York**

Amy Grillo, MA, CCC-SLP, CERT.AVP  
134 West 26th Street, Suite 606  
New York, NY 10001  
Phone (212) 604-9360  
Email CitySoundsAG@verizon.net

**Pediatric Associates for Language and Speech**

Debra K. Hagen, MA, CCC  
333 W. 57th Street  
New York, NY 10019  
Phone (212) 245-2455  
Email PALS333@aol.com

**Jeremie Hafitz, MPHI, CCC**

27 Wildwood Terrace  
Glen Ridge, NJ 07028  
Phone (973) 743-6032

**Phyliss Fabricant, MA, CCC-SLP**

80 East End Avenue  
New York, NY 10028  
Phone (212) 628-4708

**Sperling-Ratiner Speech Pathology Associates**

Sharon Ratiner, MA, CCC-SP  
351 Main Street  
Metuchen, NJ 08840  
Phone (732) 321-1780  
Email SRatiner@aol.com

**Patricia Walsh-Kay, MED, SLP**

Speech and Language Pathologist  
935 Park Avenue, Suite 1D  
New York, NY 10028  
Phone (212) 472-1910

**Other Resources**

**Daycare Centers**

**A Brighter Today (California Area)**

[www.abrightertoday.org](http://www.abrightertoday.org)

A Brighter Today is a non-profit day care center with two programs: an infant and toddler program (for ages 1 month to 23 months), and a pre-school program (for ages 2 to 5 years). The center employs a licensed vocational nurse, staffing for non-ambulatory children who weigh more than 25 pounds, an infant pre-school teacher and a part-time nutritionist. The teachers on staff have masters degrees and experience with children affected by epilepsy and cerebral palsy.

**Special Needs Activity Center for Kids (SNACK)**

At "Go Fish"  
220 East 86th Street, LL (Between 2nd and 3rd)

New York, NY 10028  
Phone (212) 439-9996  
Fax (212) 439-9995  
Email: [info@snacknyc.org](mailto:info@snacknyc.org)  
[www.snacknyc.com](http://www.snacknyc.com)

SNACK provides a supportive and non-competitive program that has been designed specifically for special needs children from infants to age 12. SNACK is the brainchild of a mother of a boy with developmental disabilities. SNACK includes music and art, group/play socialization, behavior management, and having lots of fun!

## Dentists

**Michael King, DDS**  
30 East 40th Street  
New York, NY 10001  
Phone (212) 986-2039

**Rainbow Kids Dental**  
Sungki Lee, DDS  
3900 Park Avenue  
Edison, NJ 08820  
Phone (732) 452-0100  
[www.rainbowkidsdental.com](http://www.rainbowkidsdental.com)

**The Matheny Center of Medicine and Dentistry**  
PO Box 339, Highland Avenue  
Peapack, NJ 07977  
Phone (908) 234-0011 x 771  
Fax (908) 719-2137  
[www.matheny.org](http://www.matheny.org)  
The Matheny Center is a “one-of-a-kind facility for children and adults with disabilities.”

# Disability Resources

## **National Dissemination Center (NICHCY)**

P.O. Box 1492

Washington, D.C. 20013

Phone (800) 695-0285

[www.nichcy.org](http://www.nichcy.org)

Federal government information agency.

## **The Interdisciplinary Council on Developmental and Learning Disorders, "Resource Guide for Parents by Parents"**

Phone (301) 656-2667 [www.icdl.com](http://www.icdl.com)

Comprehensive resource guide on therapies, biomedical interventions, testing, educational services, legal and insurance information.

## Catalogues for Special Needs Equipment

### **SportTime Catalogues**

Phone (800) 850-8602

[www.abilitations.com](http://www.abilitations.com)

**Abilitations** is a catalog that provides movement activity products, equipment and sensory products designed specifically for the changing needs of children.

**Integrations** is a catalog dedicated to children who learn and process information differently. This catalogue is a valuable resource for teachers of different learners, speech pathologists, special educators, occupational therapists, and parents.

**Sportime** is an innovative physical education catalogue and resource guide with over 400 pages of products for programs K through adult.

### **Flaghouse Special Populations Catalogue**

Phone (800) 793-7900

www.flaghouse.com

Software, assistive devices, strollers, mobility aids, and more.

## Financial Planning

### **Disabled and Alone/Life Services for the Handicapped, Inc.**

61 Broadway Suite 510

New York, NY 10006

Contact: Lee Alan Ackerman, Executive Director

Phone (800) 995-0066 and (212) 532-6740

Email [info@disabledandalone.org](mailto:info@disabledandalone.org)

[www.disabledandalone.org](http://www.disabledandalone.org)

Life Services helps families do sensible planning for and with their disabled sons or daughters, preparing for when they will no longer be able to provide care (due to incapacity or death); provides advocacy and oversight after the death of the parents, according to their written instructions and the special needs of the person; and advises families, attorneys and financial planners about “life planning” for a person with a disability. Life Services gives parents an answer to the question, “Who will look after our child when we are gone?”

### **UJA-Federation of New York**

Director: Stacey Ferber

130 East 59th Street

New York, NY 10022

Phone (212) 836-1150

Fax (212) 836-1172

[www.ujafedny.org](http://www.ujafedny.org)

The UJA-Federation Community Trust for disabled adults is designed to assist families in providing for the future needs of a physically, mentally, or developmentally disabled family member. It is a third party master trust in which a family member or friend sets up an account using his or her own funds. By opening a trust account, a concerned party can provide for both financial and advocacy needs of the disabled individual for the individual’s lifetime.

### **Make-A-Wish Foundation**

New York (516) 944-6212

New Jersey (908) 964-5055

Connecticut (203) 261-9044

[www.wish.org](http://www.wish.org)

The Make-A-Wish Foundation is the largest wish-granting charity in the world. Their mission is to, "Grant the wishes of children with life-threatening illnesses and to enrich the human experience with hope, strength and joy". Make-A-Wish grants the wishes of children that are under the age of 18. They accept referrals, which are kept strictly confidential. Children referred to the foundation are determined to be eligible by their physicians. To refer a child, please contact your local Make-A-Wish chapter.

## Medical Identification Bracelets

### **Medic Alert**

Phone (888) 633-4298

[www.medicalert.org](http://www.medicalert.org)

Medic Alert will notify family members of an emergency, and hospitals can call a toll free number to access medical information, including current medications. The Medic Alert service costs \$35 for the first year and \$20 thereafter. A stainless steel bracelet is included in the first year's dues, and fancier bracelets can be purchased for prices ranging from \$15 to \$700.

### **About Me Jewelry**

[www.ebiz.netopia.com/aboutme/door/](http://www.ebiz.netopia.com/aboutme/door/)

Phone (877) 524-5977

email: [aboutmejewelry@gmail.com](mailto:aboutmejewelry@gmail.com)

Unique handmade beaded medical alert jewelry that children will want to wear, custom made by a mother of a child with diabetes. As your

child grows, About Me Jewelry will resize your child's bracelet for a nominal fee. Prices range from \$38 to \$83, and engraving costs \$6 to \$12, depending on the number of lines.

## Miscellaneous Tips from Parents

"My son was on liquid phenobarbital and couldn't stand the taste. The pharmacist suggested a bubblegum flavor because it was the best flavor at masking the yucky taste. Some parents don't realize that many liquid medications can be flavored."

"VO5 Hot Oil treatment is great at getting the final bits of EEG glue out of my daughter's hair."

"My son was throwing up and couldn't eat. His medication level dropped quickly and he had two grand-mal seizures in a row. It taught us to keep extra medication in chewable tablet form and rectal Valium gel in our house so we can try to avoid this problem in the future. Ask your doctor about special safety precautions you can take that will help you avoid emergencies."

"You may wish to consult the 'Epilepsy Education, Management and Prevention Activities Database (EEPAD),' which is produced by the National Center for Disease Control and Prevention. The database contains information about the application of effective epilepsy early detection and control, program activities, education and prevention efforts. The EEPAD provides bibliographic citations and abstracts for journal articles, books/book chapters, papers, video recordings, and more, and their website is [www.cdc.gov/cdp](http://www.cdc.gov/cdp)."

"MedlinePlus is a goldmine of good health information from the National Library of Medicine. MedlinePlus has information from the National Institutes of Health, lists of hospitals and physicians, a medical encyclopedia and a medical dictionary, health information in Spanish, information on prescription and nonprescription medications, and links to clinical trials. There is no advertising on the site, and MedlinePlus does not endorse any company or product. Their websites are [www.nlm.nih.gov/medlineplus/medlineplus.html](http://www.nlm.nih.gov/medlineplus/medlineplus.html) and [www.medlineplus.gov](http://www.medlineplus.gov)."

# Nursing Organizations

## **National Association of School Nurses**

[www.nasn.org](http://www.nasn.org)

The organization of school nurses in the US.

## **New York State Association of School Nurses**

[www.nysasn.org](http://www.nysasn.org)

The organization for school nurses in NY. Contains links to government health initiatives, including National Epilepsy Month.

# Protective Head Gear

## **Plum Enterprises**

Phone (800) 321-PLUM or (610) 783-7377

[www.plument.com](http://www.plument.com)

Plum Enterprises makes protective headgear that is lightweight, shock absorbent, colorful and comfortable. “Protectacap” helmets cost between \$132 and \$229, depending on size. A firmer “Protectacap Plus” model is also available, and prices range from \$164 to \$287.

# Psychologists and Neurologists

Many wonderful psychologists and neuropsychologists who specialize in epilepsy can be found at your local Comprehensive Epilepsy Center (CEC). For a listing of local CECs, call your local Epilepsy Foundation, or contact the National Association of Epilepsy Centers, listed on page 21.

**Gabriela Hohn, Ph.D.**

Psychological Assessments & Solutions, P.C.

153 Waverly Place, 2nd Floor Suite

New York, NY 10014

Phone (212) 691-0291

Fax (917) 606-1022

Email [geh6@columbia.edu](mailto:geh6@columbia.edu)

Licensed Clinical Psychologist and Neuropsychologist specializing in working with children and adolescents. Areas of specialty include seizure disorders and epilepsy, ADHD, learning disabilities, behavioral problems and stress reactions.

## Psychotherapists

**Sandra Greenbaum, ACSW**

27 West 72nd Street, Suite 319

New York, NY 10023

Phone (212) 362-3475

\*Specializes in Children and Teenagers

## Seizure Alert Dogs

**Canine Partners for Life**

P.O. Box 170

Cochranville, PA 19330-0170

Phone (610) 869-4902 ext 221

Email [info@k94life.org](mailto:info@k94life.org)

<http://www.k94life.org/>

### **The Delta Society**

875 124th Ave NE, Ste 101  
Bellevue, WA 98005  
Phone (425) 679-5500  
Fax (425) 679-5539  
Email [info@deltasociety.org](mailto:info@deltasociety.org)  
<http://www.deltasociety.org/>

### **Paws With A Cause**

4646 South Division  
Wayland MI 49348.  
Phone (800) 253-7297  
<http://www.pawswithacause.org/>

## **Sign Language for Babies, Toddlers, and Children**

### **Baby Fingers**

Founding Director: Lora Heller, MS, MT-BC

Phone (212) 874-5978

Email [info@mybabyfingers.com](mailto:info@mybabyfingers.com)

[www.mybabyfingers.com](http://www.mybabyfingers.com)

Baby Fingers classes help to build a stronger communication bond between parent and baby. Classes are open to children who are hearing, hard-of-hearing, non-verbal, and deaf, as well as to parents whose children have a variety of special needs.

## **The Son-Rise Program**

2080 South Undermountain Road

Sheffield, MA USA 01257

Phone (413) 229-2100 or (877) SONRISE (766-7473)

Fax (413) 229-3202

[www.son-rise.org](http://www.son-rise.org)

The Son-Rise Program is a nonprofit, federally tax-exempt, charitable organization that believes that parents are their child's best resource. Our educational program is designed not only to work with children, but parents as well. We teach parents concrete educational and attitudinal tools and techniques to help them be the most effective teachers and trainers that their children can have, enabling their children to dramatically improve in all areas of learning, development, communication and skill acquisition. The teaching staff of The Autism Treatment Center of America™ combines over 100 years experience of working with children using The Son-Rise Program. We have worked with more than 22,000 parents and professionals from around the world ó delivering proven results for over 25 years.