

faces

FINDING A CURE FOR EPILEPSY & SEIZURES

*presents...*

# Pediatric Epilepsy Resource Handbook

Third Edition



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



SCHOOL OF MEDICINE  
NEW YORK UNIVERSITY

DISCLAIMERS:

*Descriptions of organizations in this guide were submitted by the organization itself or were taken from their website.*

*Therapists were recommended by parents of children with epilepsy.*

*Resources in this guide are not necessarily endorsed by the NYU Comprehensive Epilepsy Center, faces, or their employees.*

*This guide is a work in progress. To add a resource for the next edition of this guide, or to request additional copies, please contact the faces office or use the form at the back of this guide.*

*Special thanks Mark Farley for helping us update the third edition of the Pediatric Epilepsy Resource Guide.*

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# 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**

4351 Garden City Drive  
Landover, MD 20785  
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**

*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.*

## **Exceptional Parent**

65 East Route 4  
River Edge, NJ 07661  
Phone (800) EPARENT  
[www.exceptionalparent.com](http://www.exceptionalparent.com)

*Continuing 34 award-winning years of providing information, support, ideas, encouragement and outreach for parents and families of children with disabilities, and the professionals who work with them.*

# New York

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

930 Willow Brook Road  
Staten Island, NY 10312  
Phone (718) 987-0940  
Fax (718) 987-8194  
Contact: Roseanne DeRenzo  
Email [info@chrissyandfriends.org](mailto:info@chrissyandfriends.org)  
[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)**

120 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 New York State and to improve the epilepsy service system throughout New York.*

**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

Email [main@epilepsynyc.org](mailto:main@epilepsynyc.org)

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

*EFNYC helps individuals and families affected by epilepsy achieve their highest level of physical, social, and emotional well being. We offer a variety of programs and services including counseling, education seminars on seizures*

*and first aid, special fund raising events and the Adventurers' Club. The Adventurers' 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 (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, Saint Lawrence, Warren and Washington.*

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

**Rochester Office**

1650 South Avenue, Suite 300

Rochester, NY 14620

Phone (800) 728-7930

Fax (585) 442-6305

Email [info@epilepsy-uny.org](mailto:info@epilepsy-uny.org)

[www.epilepsy-uny.org](http://www.epilepsy-uny.org)

## **Syracuse Office**

800 South Wilbur Avenue

Syracuse, NY 13204

Phone (315) 473-6974 or (877) 214-2715

Fax (315) 473-6996

[www.epilepsy-uny.org](http://www.epilepsy-uny.org)

## **Binghamton Office**

3 Otseningo Street, 2<sup>nd</sup> Floor

Binghamton, NY 13903

Phone (607) 722-6822

Fax (607) 722-5646

[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

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, 4<sup>th</sup> Floor

New York, NY 10010

Phone (212) 677-8550

Fax (212) 677-5825

Email [contact@epilepsyinstitute.org](mailto:contact@epilepsyinstitute.org)

[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.*

## **Finding A Cure for Epilepsy & Seizures (faces)**

### **NYU Comprehensive Epilepsy Center/NYU Tuberous Sclerosis Center**

724 Second Avenue

New York, NY 10016

Phone (212) 871-0245

Fax (212) 871-1823

[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.*

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

7 East 85<sup>th</sup> Street, Suite A3

New York, NY 10028

Phone (212) 665-PACE

Fax (212) 327-3075

Email [pacenyemail@aol.org](mailto:pacenyemail@aol.org)

[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).*

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

116 East 16<sup>th</sup> Street, 5<sup>th</sup> Floor

New York, NY 10003

Phone (212) 677-4650

Fax (212) 254-4070

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

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

[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

Fax (732) 528-4744

Email [fsnj@familysupport.com](mailto:fsnj@familysupport.com)

[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 (800) 899-3745

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 and 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

Phone (860) 632-1485

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

[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.*

### **Westport Special Education Parent Teachers Association (SEPTA)**

RESPECT Program

Westport Townhall

110 Myrtle Avenue

Westport, CT 06880

Phone (203) 256-1834

Fax (203) 256-9205

Email [westportsepta@aol.com](mailto:westportsepta@aol.com)

<http://myschoolonline.com/site/0,1876,11228-169527-12-13867,00.html>

*Recreation, sports and social programs for children with special needs (ages 3.5 to 18 years) offering soccer, tennis, roller-blading, ice skating, dance, art, basketball, swimming, and softball. Activities are non-competitive and based on skill building. SEPTA also provides an on-line list service for brothers and sisters who have siblings with special needs. For more information visit [www.thearc.org/siblingsupport/](http://www.thearc.org/siblingsupport/).*

## **Summer Camps (Tri-State )**

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

Staten Island, NY

Contact: Julie Larsen

Phone (718) 317-2255

*This camp is designed for children ages 5-12. There are four sessions each lasting two weeks 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: Russell Berger

Phone (856) 858-5900

Email [rberger@efnj.com](mailto:rberger@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: Allison DuBois

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: Beth Riley

Phone (800) 361-5885

[www.efwp.org/programs/programs08.shtml](http://www.efwp.org/programs/programs08.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 12. 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, NY

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 80's 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

*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 73<sup>rd</sup> Street

New York, NY 10021

Phone (212) 639-0100

Fax (212) 472-0376

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

*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.*

## **The Finding A Cure for Epilepsy and Seizures (faces) Apartments**

Skirball Residential Towers

564 First Avenue

New York, NY 10016

Phone (212) 871-0245

Email [nyufaces@yahoo.com](mailto:nyufaces@yahoo.com)

*The faces apartments give priority to children with epilepsy seeking medical*

*treatment at NYU Medical Center, but will provide housing to other patients if space is available. Call at least two months in advance for best availability. The apartments are free of charge.*

## Clinical Trials

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

## Special Education Information

### **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**

By Winifred Anderson et al

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

### **Sensory Integration Network**

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

*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

Executive Director: Michael Termini, Psy.D.

Phone (212) 280-4473

Fax (212) 280-4477

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

Email [information@cookecenter.org](mailto:information@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 29<sup>th</sup> Street

New York, NY 10016

Director of Admissions: Wendy Federico

Phone (212) 722-0610

Fax (212) 722-1387

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

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

47 Clove Road

Upper Montclair, NJ 07043

Director: Antoinette Spiotta

Phone (973) 655-4357

Fax (973) 655-5155

## **Eagle Hill School**

45 Glenville Road

Greenwich, CT 06831

Headmaster: Mark Griffin, Ph.D.

Director of Admissions: Rayma-Joan Griffin

Phone (203) 622-9240

Fax (203) 622-0914

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

## **Ferncliff Manor**

1154 Saw Mill River Road

Yonkers, NY 10710

Director: Willaim Saich

Phone (914) 968-4854

Fax (914) 968-4857

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

## **The Forum School**

107 Wyckoff Avenue

Waldwick, NJ 07463

Director: Steven Krapes, Ed.D.

Phone (201) 444-5882

Fax (201) 444-4003

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

## **The Gateway School**

236 Second Avenue

New York, NY 10003

Director: Robert B. Cunningham, M.A., Ed.M.

Phone (212) 777-5966

Fax (212) 777-5794

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

**The Gillen Brewer School**

1190 Park Avenue

New York, NY 10128

Director: Donna Kennedy

Phone (212) 831-3667

Fax (212) 831-5254

**Hawthorne Country Day School**

5 Bradhurst Avenue

Hawthorne, NY 10532

Director: Christopher McDonough, PhD, BCBA

Phone (914) 592-8526

Fax (914) 592-3227

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

**The Midland School**

94 Reading Road

PO Box 5026

North Branch, NJ 08876

Director: Phillip Gartlan

Phone (908) 722-8222

Fax (908) 772-6203

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

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

95 Bradhurst Avenue

Valhalla, NY 10595

Superintendent: Ellen Bergman, Ph.D.

Phone (914) 347-1800 ext. 201

Fax (914) 347-2307

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

**Parkside School**

48 West 74<sup>th</sup> Street

New York, NY 10023

Administrative Director: Albina Miller

Phone (212) 721-8888

Fax (212) 721-1547

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

### **The Stephen Gaynor School**

22 West 74<sup>th</sup> Street

New York, NY 10023

Director: Scott Gaynor, Ph.D.

Phone (212) 787-7070

Fax (212) 787-3312

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

### **The Smith School**

131 West 86<sup>th</sup> Street

New York, NY 10024

Director: Karen Smith

Phone (212) 879-6354

Fax (212) 879-0962

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

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

45 Park Avenue

Yonkers, NY 10703

Director: Thomas Timmons, Ph.D.

Phone (914) 376-4300

Fax (914) 965-7059

## **Education Consultants**

### **Patricia Sokolow**

407 3<sup>rd</sup> 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)**

638 Prospect Avenue  
Hartford, CT 06105  
Phone (860) 586-7505  
[www.aesnet.org](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 Boulevard, Suite 200  
Minneapolis, MN 55416  
(888) 525-6232 or (952) 525-4526  
[www.naecepilepsy.org](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 [NYUfaces@yahoo.com](mailto:NYUfaces@yahoo.com) to receive a copy of the chart via fax or mail.*

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

1100 15<sup>th</sup> Street, NW  
Washington, DC 20005  
*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 Road, Suite 2A  
Eastchester, NY 10709  
Phone (914) 337-3026

## Art Therapists

### **Lesley Achitoff, MPS**

160 West End Avenue, Apt 3D  
New York, NY 10023  
Phone (212) 807-0546  
Email [nofony@RNC.com](mailto:nofony@RNC.com)

### **Elizabeth Coss, MA, ATR-BC**

15 Wyckoff Street, #17  
Brooklyn, NY 11201  
Phone (646) 522-7099  
Email [eqc9977@nyu.edu](mailto:eqc9977@nyu.edu)

## 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

### **KidsCare Institute, Inc.**

President: Colleen Kennedy, PT  
3196 Kennedy Boulevard, 3<sup>rd</sup> floor  
Union City, NJ 07087  
Phone (201) 223-4949

*The KidsCare Institute, Inc. 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:*

Director: Gregory Santucci, MS, OTR  
Pediatric Occupational Therapist, certified in Sensory Integration  
260 Prospect Avenue, Apt 662  
Hackensack, NJ 07601  
Phone (973) 563-4544  
Email [Gregorysantucci@aol.com](mailto: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](mailto:potschaye@aol.com)

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

39 West 14<sup>th</sup> Street, Suite 307  
New York, NY 10011  
Phone (212) 414-2777  
Email [jaymerich.ot@earthlink.net](mailto:jaymerich.ot@earthlink.net)

### **Lori Rothman, OTR**

144 West 86<sup>th</sup> Street, #1B  
New York, NY 10024  
Phone (212) 595-7782  
Email [LRoth123@aol.com](mailto:LRoth123@aol.com)

### **Sara Schlusel, OTR**

100 Lybecker Street  
Englewood, NJ 07631  
Phone (201) 569-0767  
Email [Mdotlevana@aol.com](mailto: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](mailto:Sugu@earthlink.com)

**Cindy Rosenbloom, PT**

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

**Hospital for Joint Diseases**

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

**Helene Widman, PT**

Phone (917) 992-4065  
Email [KidPT64@aol.com](mailto:KidPT64@aol.com)

**Speech Therapists**

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

Speech and Language Pathologist  
95-11 101 Avenue  
South Ozone Park, NY 11416  
Phone (718) 641-6723

**Pam Davis**

Speech and Language Pathologist  
1060 5<sup>th</sup> Avenue  
New York, NY 10128  
Phone (212) 831-4344  
Email [NUYKS@aol.com](mailto:NUYKS@aol.com)

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

New York Office:  
107 West 82<sup>nd</sup> Street, Suite 103  
New York, NY 10024  
Phone (212) 712-2014  
Email [Zoulicat2@aol.com](mailto: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](mailto:Tikes01@aol.com)

**City Sounds of New York**

Amy Grillo, MA, CCC-SLP, CER.AVP

134 West 26<sup>th</sup> Street, Suite 606

New York, NY 10001

Phone (212) 604-9360

Email [CitySoundsAG@verizon.net](mailto:CitySoundsAG@verizon.net)

**Pediatric Associates for Language and Speech**

Debra K. Hagen, MA, CCC

333 West 57<sup>th</sup> Street

New York, NY 10019

Phone (212) 245-2455

Email [PALS333@aol.com](mailto: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

Email [SRatiner@aol.com](mailto: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 86<sup>th</sup> Street, LL

New York, NY 10028

Phone (212) 439-9996

Fax (212) 439-9995

[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 40<sup>th</sup> Street

New York, NY 10016

Phone (212) 986-2039

#### **Rainbow Kids Dental**

Sungki Lee, DDS

3900 Park Avenue

Edison, NJ 08820

Phone (732) 452-0100

## **The Matheny Center of Medicine and Dentistry**

PO Box 339, Main Street

Peapack, NJ 07977

Phone (908) 234-0011 x 771

[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 Information Center for Children and Youth with Disabilities (NICHCY)**

PO Box 1492

Washington, DC 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) 850-8603

[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.*

***Sporttime** 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](http://www.flaghouse.com)

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

## Financial Planning

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

352 Park Avenue South, 11<sup>th</sup> Floor

New York, NY 10010

Contact: Roslyn Brilliant, 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: Morton Asch

130 East 59<sup>th</sup> Street

New York, NY 10022

Phone (212) 836-1339

Fax (212) 836-1172

[www.ujafed.NY.org](http://www.ujafed.NY.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 with prices ranging from \$15 to \$700.*

### **About Me Jewelry**

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

Phone (877) 639-1004

*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 New York. Contains links to government health initiatives, including National Epilepsy Month.*

## Protective Head Gear

### **Plum Enterprises**

500 Freedom View Lane

PO Box 85

Valley Forge, PA 19481

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

Fax (610) 783-7577

[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 Neuropsychologists

*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 20.*

### **Gabriela Hohn, Ph.D.**

Psychological Assessments & Solutions, P.C.

153 Waverly Place, 2<sup>nd</sup> 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 72<sup>nd</sup> Street, Suite 319

New York, NY 10023

Phone (212) 362-3475

## Seizure Alert Dogs

### **Canine Partners for Life**

PO Box 170

Cochranville, PA 19330-0170

Phone (610) 869-4902

Fax (610) 869-9785

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

[www.k94life.org](http://www.k94life.org)

### **The Delta Society**

875 124th Avenue NE, Suite 101

Bellevue, WA 98005

Phone (425) 226-7357

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

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

**Paws With A Cause**  
4646 South Division  
Wayland, MI 49348  
Phone (800) 253-7297  
[www.pawswithacause.org](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 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 — delivering proven results for over 25 years.*



## Recommend Resources for the 2006 Edition

Parent Name: \_\_\_\_\_

Name: \_\_\_\_\_

Titles (O.T., PhD, etc.): \_\_\_\_\_

Address: \_\_\_\_\_

City, State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Email: \_\_\_\_\_

Website: \_\_\_\_\_

Name: \_\_\_\_\_

Titles (O.T., PhD, etc.): \_\_\_\_\_

Address: \_\_\_\_\_

City, State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Email: \_\_\_\_\_

Website: \_\_\_\_\_

Please send to: NYU-faces  
724 Second Avenue  
New York, NY 10016  
Fax: 212.871.1823  
Email: [NYUfaces@yahoo.com](mailto:NYUfaces@yahoo.com)





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f a  e s

FINDING A **CURE** FOR EPILEPSY & SEIZURES

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NYUfaces@yahoo.com  
[www.nyufaces.org](http://www.nyufaces.org)