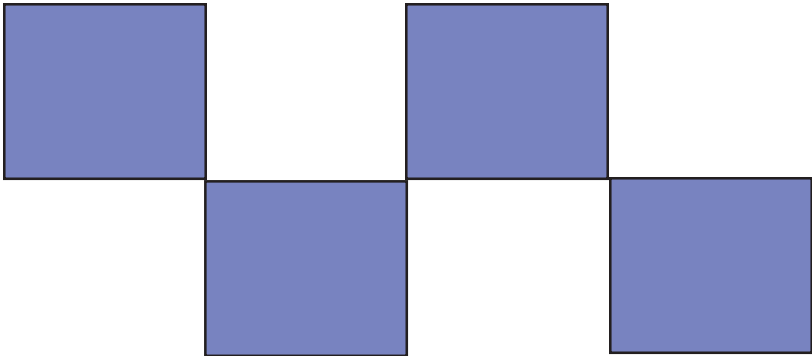


Finding A Cure for Epilepsy
and Seizures
Presents...

Pediatric Epilepsy Resource Handbook

Second Edition



finding a cure for epilepsy & seizures (faces)

NYU Comprehensive Epilepsy Center

403 E. 34th Street, 4th Floor

New York, NY 10016

www.nyufaces.org

NYU
Medical
Center



SCHOOL OF MEDICINE
NEW YORK UNIVERSITY



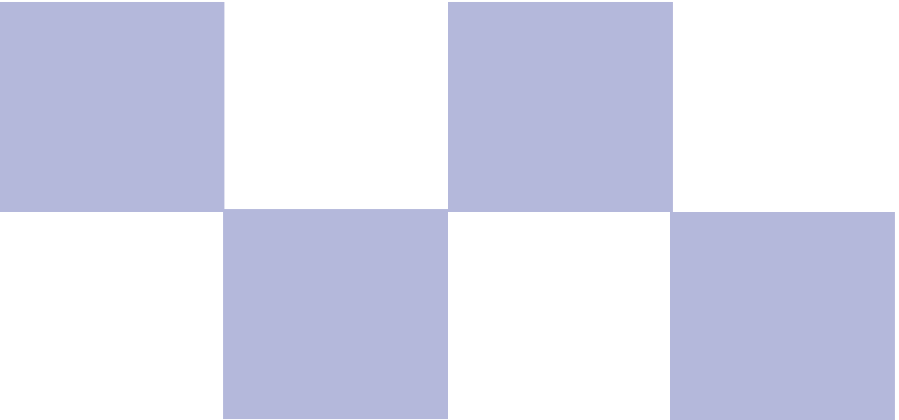
DISCLAIMERS:

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 to parent Catherine Genna, and interns Rachel Kessler and Jessica Levine for helping us to improve the second edition of the Pediatric Epilepsy Resource Guide.

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National Epilepsy Resources

Epilepsy Foundation

4351 Garden City Dr.
Landover, MD 20785
Phone (410) 828-7700 or (800) 332-1000
www.epilepsyfoundation.org

EF is 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

www.exceptionalparent.com

EP's on-line resource. Continuing 33 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.

Parents Against Childhood Epilepsy, Inc. (PACE)

7 East 85th St., Suite A
New York, NY 10028
Phone (212) 665-PACE
www.paceusa.org

Parents Against Childhood Epilepsy, Inc. was 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.

New York

Chrissy and Friends, Inc.

62 Otis Ave.

Staten Island, NY 10306

Phone (718) 987-0940

Contact: RoseAnne DeRenzo

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 Ave.

Albany, NY 12210

Phone (518) 434-4360

Fax (518) 434-4542

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 Ave.

Garden City, NY 11530

Phone (516) 739-7733

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 Ave., Suite 1202

New York, NY 10001

Phone (212) 633-2930

Fax (212) 633-2991

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 & 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 Toll Free (800) 894-3223

Fax (518) 452-1282

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, St. Lawrence, Warren and Washington.

Epilepsy Foundation of Rochester-Syracuse-Binghamton

Rochester Office

1650 South Ave, Suite 300

Rochester, NY 14620

Phone (585) 442-4430, ext. 2702 (Theresa King, Community Educator)

Fax (585) 442-6305

Email 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.epilepsy-uny.org

Binghamton Office

3 Osteningo Street, 2nd Floor

Binghamton, NY 13903

Phone (607) 723-4203

Fax (607) 771-8723

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

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 Ave. South, 4th Floor

New York, NY 10010

Phone (212) 677-8550

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

403 E. 34th St., 4th Floor

New York, NY 10016

Phone (212) 779-2080

Fax (212) 779-2331

www.nyufaces.org

Faces promotes research into neuroprosthesis, magnetic stimulation, Bio-feedback, 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 St., 5th Floor

New York, NY 10003

Phone (212) 677-4650

Email info@resourcesnyc.org

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

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 Hwy 35 N.

Manasquan, NJ 08736

Phone (732) 528-8080

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 St.

Middletown, CT 06457

Phone (860) 346-1924

Fax (860) 346-1928

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 Rd.

Middletown, CT 06457-1520

Phone (860) 632-1485

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 St.

Niantic, CT 06357

Phone (800) 445-CPAC

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

Phone (203) 256-1834

Fax (203) 256-9205

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

Email septa@aol.com

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.

Summer Camps (Tri-State)

Father Drumgoole-Connelly Summer Day Camp at Mt. Loretto

Staten Island, NY

Phone (718) 317-2255

Contact: Julie Larsen

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

The Epilepsy Institute Travel Day Camp

Manhattan, NY

Phone (212) 677-8550

Contact: Pam Conford, Executive Director

A one-week travel day camp designed for young teens ages 12-16 with a primary diagnosis of epilepsy. The camp runs daily 9:00 am-4:30 pm with different trips or events around the Metropolitan area. The central meeting

area is located at 257 Park Avenue South. Siblings may be able to attend, if space allows.

The Epilepsy Foundation of New Jersey's Camp Nova

Blairstown, NJ

Contact: Russell Berger

Phone (856) 858-5900 or (609) 392-4900 x 210

Email rberger@efnj.com

www.efnj.com

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 Camp Hemlock

Hebron, CT

Contact: Deanna Newland

Phone (800) 899-EPIL

Email efct@aol.com

EFCT's one-week overnight camp is held at Easter Seals Camp Hemlocks in Hebron, Connecticut, just 25 miles east of Hartford. It is open to children and teens ages 6 to 18 who have a primary diagnosis of epilepsy. The camp, which is accredited by the American Camping Association, includes a dining hall, health center, auditorium, indoor-heated pool, greenhouse, cabins, an Arts & Crafts Center, a Nature Center, and a Challenge & Group Initiative course. All counselors receive specialized training in seizure recognition and first aid. 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.campfitch.com

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 hun-

dreds 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 arts and crafts, campfire sing-a-longs, canoeing, swimming, team games, and informative group discussions that help campers learn more about themselves. All camp staff members receive specialized training in seizure recognition and first-aid training. The medical staff includes a licensed pediatric neurologist and a registered nurse. Scholarships and financial assistance are available to eligible campers. Limited to residents of Western and Central PA.

Achieve Retreat Weekend

The Epilepsy Foundation of Eastern Pennsylvania
Schwenksville, PA

Contact: Denise Graham

Phone (215) 629-5003 x 107

www.efepa.org

Email efsepa@efsepa.org

A fun-filled weekend held at a local camp that is designed to provide a social environment of support and education for pre-teens and teens with epilepsy. Activities include volleyball and basketball, pizza and sundae parties, team building exercises, and a seminar for parents and campers interested in understanding epilepsy better. The staff includes a nurse practitioner and qualified camp counselors. A hospital and emergency services are located nearby.

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

Warsaw, NY

Contact: Randi Nunn

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. There is an on-site neurologist, and 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

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

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)

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.

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

Skirball Residential Towers

564 First Avenue

New York, NY 10016

Phone (212) 779-2080

Email 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 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 (952) 838-0190 TTY

Fax (952) 838-0199

Email fape@fape.org

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

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

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

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

Email 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 29th St.

New York, NY 10016

Director of Admissions: Ms. Twinkie Otis

Phone (212) 722-0610

Fax (212) 722-1387

www.churchillschool.com

**High functioning learning disabled*

The Demonstration Program at Montclair University

47 Clove Rd.

Upper Montclair, NJ 07043

Director: Antoinette Spiotta

Phone (973) 655-4357

Fax (973) 655-5155

Eagle Hill School

45 Glenville Rd.

Greenwich, CT 06831

Director: Mark Griffin, PhD

Phone (203) 622-9240

Fax (203) 622-0914

www.eaglehillsschool.org

**High functioning learning disabled*

Ferncliff Manor

1154 Saw Mill River Rd.

Yonkers, NY 10710

Director: Susan Seda

Phone (914) 968-4854

Fax (914) 968-4857

**Mild-severe mental retardation*

The Forum School

107 Wycoff Ave.

Waldwick, NJ 07463

Director: Steven Krapes

Phone (201) 444-5882

Fax (201) 444-4003

www.theforumschool.com

The Gateway School

236 Second Ave.

New York, NY 10003

Director: David Sherwood

Phone (212) 777-5966

Fax (212) 777-5794

www.gatewaysschool.org

**Ages 5-10*

The Gillen Brewer School

1190 Park Ave.

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 Ave.

Hawthorne, NY 10532

Director: Christopher McDonough, PhD, BCBA

Phone (914) 592-8526

Fax (914) 592-3227

www.hawthornecountryday.org

**Autism*

The Midland School

94 Readington Rd.

North Branch, NJ 08876

Director: Phillip Gartlan

Phone (908) 722-8222

**Ages 5-21*

Mt. Pleasant Blythedale Children's School

95 Bradhurst Ave.

Valhalla, NY 10595

Principal: Lisa O'Shea

Phone (914) 347-1800 ext. 201

Fax (914) 347-2307

www.blythedale.org

Parkside School

48 West 74th St.

New York, NY 10023

Administrative Director: Albina Miller

Phone (212) 721-8888

Fax (212) 721-1547

www.parksideschool.org

**Age 5-10*

The Stephen Gaynor School

22 West 74th St.

New York, NY 10023

Director: Dr. Miriam Michael

Phone (212) 787-7070

Fax (212) 787-3312

www.sgaynor.com

The Smith School

1393 York Ave.

New York, NY 10021

Director: Karen Smith

Phone (212) 879-6354

Fax (212) 879-0962

www.SmithSchool.net

Westchester School for Special Children

45 Park Ave.

Yonkers, NY 10703

Director: Thomas Timmons

Phone (914) 376-4300

Fax (914) 965-7059

**Mild-severe mental retardation*

Education Consultants**Patricia Sokolow**

407 3rd Ave.

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 Ave.

Hartford, CT 06105

(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

(612) 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) go to faces and the National Epilepsy Foundation. You may also email 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.

Therapists Recommended By Parents of Children with Epilepsy

Applied Behavioral Analysis Therapists

Programs for Little Learners, LLC

Eileen Boothe, OT and Jennifer Strazzeri, OT

Executive Directors

10 Wilsey Square, Suite 248
Ridgewood, NJ 07450
Phone (201) 251-3800
www.programsforlittlelearners.com
and

266 White Plains Rd., Suite 2A
Eastchester, NY 10709
Phone (914) 337-3026

Art Therapists

Lesley Achitoff, MPS

160 West End Ave., Apt 3D
New York, NY 10023
Phone (212) 807-0546

Elizabeth Coss, MA, ATR-BC

15 Wyckoff St., #17
Brooklyn, NY 11201
Phone (646) 522-7099
Email 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 Ave., Suite 203-205
Livingston, NJ 07039
Phone (973) 535-5010

KidsCare Institute, Inc.

3196 Kennedy Blvd., 3rd 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 obser-

vation 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 Ave., Apt 662
Hackensack, NJ 07601
Phone (973) 563-4544
Email Gregorysantucci@aol.com

President: Colleen Kennedy, PT
3196 Kennedy Blvd., 3rd floor
Union City, NJ 07087
Phone (201) 223-4949

Pediatric Occupational Therapy Services

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

Jayme Lewin Rich, MPA, OTR/L

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

Lori Rothman, OTR

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

Sara Schlussel, OTR

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

Physical Therapists

Susan Guzzardo, PT, DPT

68-16 Eliot Ave.

Middle Village, NY 11379

Phone (212) 463-0400 x 647

Sugu@earthlink.com

Cindy Rosenbloom, PT

6 Myrtle Ave.

Demarest, NJ 07627

Phone (201) 784-0842

Hospital for Joint Diseases

Jennifer Tisco

301 East 17th St., 4th Floor

New York, NY 10003

Phone (212) 598-6248

Helene Widman, PT

Phone (917) 992-4065

KidPT64@aol.com

Speech Therapists

Carmela Maio, MS, CCC-SLP, TSHH

Speech and Language Pathologist

95-11 101 Ave.

South Ozone Park, NY 11416

Phone (718) 641-6723

Pam Davis

Speech and Language Pathologist

1060 5th Ave.

New York, NY 10128

Phone (212) 831-4344

Email NUYKS@aol.com

Rachel Fisch-Kaplan, MS, CCC-SLP

New York Office:

107 West 82nd St., Suite 103

New York, NY 10024

Phone (212) 712-2014

Email Zoulicat2@aol.com

New Jersey Office:

48 Maple St.

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 Ave., 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 St., 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 St.

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 E. End Ave.

New York, NY 10028

Phone (212) 628-4708

Sperling-Ratiner Speech Pathology Associates

Sharon Ratiner, MA, CCC-SP

351 Main St.

Metuchen, NJ 08840

Email SRatiner@aol.com

Patricia Walsh-Kay, MED, SLP

Speech and Language Pathologist

935 Park Ave., Suite 1D

New York, NY 10028

Phone (212) 472-1910

Other Resources

Daycare Centers

A Brighter Today (California Area)

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 E. 86th Street, LL (Between 2nd and 3rd)

New York, NY 10028

Phone (212) 439-9996

Fax (212) 439-9995

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 dis-

abilities. SNACK includes music and art, group/play socialization, behavior management, and having lots of fun!

Dentists

Michael King, DDS

30 East 40th St.
New York, NY 10016
Phone (212) 986-2039

Rainbow Kids Dental

Sungki Lee, DDS
3900 Park Ave.
Edison, NJ 08820
Phone (732) 452-0100

The Matheny Center of Medicine and Dentistry

PO Box 339, Main St.
Peapack, NJ 07977
Phone (908) 234-0011 x 771

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)

P.O. Box 1492
Washington, D.C. 20013
Phone (800) 999-5599

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

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

***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.

352 Park Ave. South, 11th Floor

New York, NY 10010

Contact: Roslyn Brilliant, Executive Director

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

Email info@disabledandalone.org

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 E. 59th Street

New York, NY 10022

Phone (212) 836-1339

Fax (212) 836-1172

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

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

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/

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 (EPPAD)," 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 EPPAD provides bibliographic citations and abstracts for journal articles, books/book chapters, papers, video recordings, and more, and their website is 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 and www.medlineplus.gov.”

Nursing Organizations

National Association of School Nurses

www.nasn.org

The organization of school nurses in the US.

New York State Association of School Nurses

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

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 21.

Gabriela Hohn, Ph.D.

Psychological Assessments & Solutions, P.C.

153 Waverly Pl., 2nd Floor Suite

New York, NY 10014

Phone (212) 691-0291

Fax (917) 606-1022

Email geh6@columbia.edu

<http://G.E.Hohn.PhD.home.att.net>

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 W. 72nd St., Suite 319

New York, NY 10023

Phone (212) 362-3475

**Specializes in Children and Teenagers*

Sign Language for Babies, Toddlers, and Children

Baby Fingers

Founding Director: Lora Heller, MS, MT-BC

Phone (212) 874-5978

Email info@mybabyfingers.com

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 S. Undermountain Rd.

Sheffield, MA USA 01257

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

Fax (413) 229-3202

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:

Type of Resource (Organization, Therapist, etc.):

Name:

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

Affiliation (if any):

Address:

Address 2:

City, State:

Zip:

Phone:

Fax:

Email:

Website:

Type of Resource (Organization, Therapist, etc.):

Name:

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

Affiliation (if any):

Address:

Address 2:

City, State:

Zip:

Phone:

Fax:

Email:

Website:

Please send to:

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11E. 32nd Street, Basement Office

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facescoordinator@yahoo.com (e-mail)

www.nyufaces.org