

They never ask

It's still hard for me to say epilepsy.

People have this picture in their minds.

The only true disability is

a lack of knowledge

It's still hard for me

They never ask

People ask how do you do it? People ha

REACH OUT

A Resource Guide for Parents of Teens with Epilepsy

People ask how do you do it? People ha

They never ask what can I do for

a lack of knowledge

It's still hard for me to s

You want your child to be like every

o be like every

It's still hard for me to say epilepsy.

The only true disability is

They never ask

The “Reach Out” resource guide is intended to be a listing of some of the most helpful resources available to you as a parent of a teen with epilepsy.

THIS GUIDE INCLUDES:

- NATIONAL ORGANIZATIONS DEDICATED TO ADDRESSING EPILEPSY
- BROCHURES, GUIDES, AND NEWSLETTERS
- SIBLING SUPPORT ORGANIZATIONS
- BOOKS
- HEALTH WEB SITES
- ADDRESSING TEEN ISSUES
- ADDITIONAL RESOURCES
- RESOURCES IN SPANISH

LACK OF KNOWLEDGE

“It’s still hard for me to sa

People have this pi

to be like every

“It’s still hard for me to say” epilepsy

other teenager

National Organizations

Dedicated to Addressing Epilepsy

Government Agencies

Centers for Disease Control and Prevention (CDC)

CDC, an agency of the U.S. Department of Health and Human Services, promotes health and quality of life by preventing and controlling disease, injury, and disability. Within CDC, the National Center for Chronic Disease Prevention and Health Promotion is charged with preventing death and disability from chronic diseases and with promoting maternal, infant, and adolescent health and healthy personal behaviors. The CDC epilepsy program, which is within this center, conducts epilepsy program activities in the areas of improving care, improving communication and combating stigma, self-management, surveillance and prevention research, increasing public awareness and knowledge, and strengthening partnerships.

NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION
AND HEALTH PROMOTION

Centers for Disease Control and Prevention
4770 Buford Highway, N.E., MS K51
Atlanta, GA 30341-3724
www.cdc.gov/epilepsy

National Institute of Neurological Disorders and Stroke (NINDS)

NINDS is an agency of the U.S. Department of Health and Human Services and a component of the National Institutes of Health. It is the leading supporter of biomedical research on disorders of the brain and nervous system.

NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE

National Institutes of Health
Building 31, Room 8A-06
Bethesda, MD 20892
(800) 352-9424
www.ninds.nih.gov

Health Resources and Services Administration (HRSA)

HRSA is an agency of the U.S. Department of Health and Human Services. Its mission is to improve and expand access to quality health care for all, including people with epilepsy.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Maternal and Child Health Bureau
Division of Services for Children with
Special Health Needs
Integrated Services Branch, 18A-18
Rockville, MD 20857
(301) 443-2170
www.hrsa.gov

Non-Government Agencies

Epilepsy Foundation (EF)

EF is a national organization that conducts research and provides education, advocacy, and other services for people living with epilepsy. The EF Web site offers detailed information on all aspects of epilepsy as well as on EF's programs and services, news, and publications.

EF state affiliates provide services on the local level in many communities. Some EF affiliates have support groups specifically for parents. For a complete listing of state affiliates or to find the one closest to you, please contact the EF.

EPILEPSY FOUNDATION

4351 Garden City Drive
Landover, MD 20785
(800) 332-1000
www.epilepsyfoundation.org

EF eCommunities

EF provides e-communities that allow for online chats and dialogue among common interest groups including parents of teens with epilepsy. For a listing of groups or to join a group, please visit www.epilepsyfoundation.org/ecommunities.

EF Resource Library

EF provides an extensive resource library on its Web site. All topics related to epilepsy including searches and information (for free or for a nominal fee to covering copying costs) are posted. Resources include:

- EpilepsyUSA—EF's bimonthly magazine and a good resource for finding out about advances in the medical and research fields, upcoming EF events, and the lives of people, including young people living with epilepsy.

- **Epilepsy: Part of Your Life**—Offers guidance on medical treatment and advice for living a healthy life, adjusting to epilepsy, reducing the frequency of seizures, and understanding associated feelings.
- **Answers to Your Questions About Epilepsy**—Written for teens. Includes answers to teens' questions on why taking medicine on time is so important; the interactions and dangers of mixing medicine, drugs, and alcohol; and the use of birth control.
- **Epilepsy: Questions and Answers About Seizure Disorders**—Offers answers to questions about epilepsy, seizures, first aid, treatment, daily life, and the EF.
- **Safety and Seizures: Tips for Living with Seizure Disorders**—Reviews safety issues that may arise when seizures occur.
- **Medicines for Epilepsy**—Discusses various types of medication.
- **Surgery for Epilepsy**—Covers current surgical treatment and testing that precedes surgery.
- **Issues & Answers. Exploring Your Possibilities: A Guide for Teens and Young Adults With Epilepsy.**

American Epilepsy Society

This national society promotes research and education for professionals dedicated to the prevention, treatment, and cure of epilepsy.

AMERICAN EPILEPSY SOCIETY
342 North Main Street
West Hartford, CT 06117-2507
(800) 586-7505
www.aesnet.org

National Association of Epilepsy Centers (NAEC)

The NAEC is a nonprofit trade association whose members include more than 60 specialized epilepsy centers across the United States. This association can help you find an epilepsy center close to your home.

NATIONAL ASSOCIATION OF EPILEPSY CENTERS
5775 Wayzata Boulevard
Suite 200
Minneapolis, MN 55416
(612) 525-4526
www.naecepilepsy.org

**“We have to
make sure
that epilepsy does not
take over the family.”**

Brochures, Guides and Newsletters

- **The ERIC Clearinghouse on Disabilities and Gifted Education**—Includes information on siblings of children with disabilities, including a list of selected citations from the ERIC database, as well as links to related internet resources and discussion groups. Available at: www.ericec.org/faq/siblings.html.
- **Facts for Families**—A series of informative fact sheets that include information on medications for children, health insurance, and how to seek help. This series is produced by the American Academy of Child and Adolescent Psychiatry. Available at: www.aacap.org/publications/factsfam/index.htm.
- **Meeting the Unique Concerns of Brothers and Sisters with Special Needs**, by Donald Meyer and Patricia Vadasy—Addresses sibling rivalry issues. Available at: www.thearc.org/siblingsupport/meetingtheconcernsof....htm.

Sibling Support Organizations

Sibling Information Network
349 Glenbrook Road
Storrs, CT 06269
(860) 486-4985

Siblings for Significant Change
350 Fifth Avenue
New York, NY 10018
(212) 643-2663

Siblings of Disabled Children
Parents Helping Parents, Inc.
3041 Olcott
Santa Clara, CA 95054
(408) 727-5775

Sibling Support Project of the ARC in the U.S.
6512 23rd Avenue, N.W. #213
Seattle, WA 98117
(206) 297-6368
www.thearc.org/siblingsupport

The Sibling Support Project can help you locate or start up a sibling group for area children with disabilities. It also provides a database of more than 350 sibling groups and programs nationwide.

Books

- A Parent's Guide to the Teenage Years
by B. B. Williamson
- Teenagers & Parents: Ten Steps for a Better Relationship
by Roger W. McIntire
- Parenting Teens With Love & Logic: Preparing Adolescents for Responsible Adulthood
by Jim Fay and Foster W. Cline
- Epilepsy: Questions and Answers
by J. W. Sanders and Yvonne Hart
- Epilepsy: 199 Answers (A Doctor Responds to His Patients' Questions)
by Andrew N. Wilner, M.D.
- Growing Up With Epilepsy: A Practical Guide for Parents
by Lynn Bennett Blackburn, Ph.D.
- The Official Patient's Sourcebook on Seizures and Epilepsy: A Revised and Updated Directory for the Internet Age
published by Icon Health Publications
- Epilepsy: The Ultimate Teen Guide
by Kathlyn Gay and Sean McGarrahan
- Let's Talk About Epilepsy
by Melanie Apel Gordon
- Women with Epilepsy: A Handbook for Health and Treatment issues
by Martha J. Morrell, M.D.
- Epilepsy and the Family: A New Guide (1999 edition)
by Richard Lechtenberg, M.D.
- Epilepsy: Patient and Family Guide
by Orrin Devinsky, M.D.
- Epilepsy: You're Not Alone
by Stacey Chillemi
- Epilepsy and Seizures: Everything You Need to Know
by Donald Weaver, M.D.
- The Last Book in the Universe
by Rodman Philbrick



Health Web Sites

In addition to the previously listed resources with Web sites, the following Internet sites may be helpful in finding out more about epilepsy and parenting.

Epilepsy

- Citizens United for Research in Epilepsy
www.cureepilepsy.org
- Washington University at St. Louis
Pediatric Epilepsy Center
www.neuro.wustl.edu/epilepsy/pediatric/index.html
- Tufts University Child & Family WebGuide
www.cfw.tufts.edu
- Epilepsy Web Ring for Parents
www.kidsepilepsy.com
- Epilepsy.com—sponsored by the Epilepsy Project
www.epilepsy.com
- British Epilepsy Association
www.epilepsy.org.uk

Addressing Teen Issues

Even though your teen has epilepsy, you'll be faced with discussing "traditional" teen issues that arise for any parent of a teen. The following Web site resources may be of help to you:

- The Partnership for a Drug-Free America
www.drugfreeamerica.com

Includes free brochure titled "Tips For Raising Drug-Free Teens" to help parents monitor their kids and be proactive in their lives. Also encourages parents to learn about drugs that are popular among teens and to know the dangers of these drugs. Parents will also find information on the increasingly popular and dangerous illegal drug Ecstasy—complete with descriptions, slang terms, and warning signs of abuse.

- Advocates for Youth "Open Up, Listen Up!"
www.advocatesforyouth.org

Collection of pamphlets, activities, multimedia reviews, and resource listings to answer parents' questions about talking with adolescents about sexuality.

- Palo Alto Medical Foundation Teen Health Series
www.pamf.org/teen

Provides young people with medically accurate information and resources about their health – in one convenient location. A resource for discussing sex with your teen.

- The Kaiser Family Foundation "Talking with Kids About Tough Issues"
www.talkingwithkids.org

Includes discussion tips on teen topics, including violence in the media, violence among friends and in relationships, and teen sexuality. Resources are provided and brochures can be downloaded.

- The National Parenting Center "Parent Talk"
www.tnpc.com/parentalk/adoles.html

Includes articles from experts on talking to teens about peer pressure, body image, sex, drug abuse, alcohol, and other topics.

Parenting

- *Working Things Out With Your Teenager*
(download this tip sheet in PDF Format)
www.families.qld.gov.au/family/familiesfirst/publications/documents/pdf/working.pdf
- University of Washington Adolescent Health Transition Project
<http://depts.washington.edu/healthtr>
- Administration for Children and Families
www.acf.dhhs.gov
- Support for Families of Children with Disabilities
www.supportforfamilies.org/internetguide
- Family Education
www.familyeducation.com
- Fathers Network
www.fathersnetwork.org
- iVillage
www.ivillage.com/topics/parenting
- Brave Kids
www.bravekids.org
- DisabilityInfo.gov
www.disabilityinfo.gov
- Parenting Adolescents
www.parentingadolescents.com

Addressing Teen Issues

(cont.)

- Public Broadcasting System "Talking with your Teen"
<http://www.pbs.org/wgbh/pages/frontline/shows/teenbrain/etc/worksheet.html>

Provides a wealth of information on teens and changes to expect through the adolescent period.

- National Institutes of Mental Health (NIMH) "Information on Children and Adolescent Issues"
www.nimh.nih.gov/publicat/childmenu.cfm

Includes information on mental disorders such as depression, anxiety, learning disabilities, and eating disorders. Articles are related to children/teens and include definitions, warning signs, and information on how to talk to your kids about mental health issues and treatment options. Also includes summaries of clinical research conducted at NIMH, teen violence prevention, and other interesting teen issues.

- Teens and Depression
www.about-teen-depression.com

Includes tips for talking to teens about depression, warning signs, and treatment options.

High School and Post High School Planning

For information on issues related to high school and post high school planning, the following resources may be of help to you:

- U.S. Department of Education
www.eric.ed.gov

Information on selecting educational programs for a disabled high school graduate.

- College Board
www.collegeboard.com

Information regarding SAT preparation and college selection.

- The Learning Disabilities Association of America
www.ldanatl.org

Information specifically for people with learning disabilities.

Additional Resources

Parent to Parent

Local affiliates of parents and parental advocates. Each state offers something different to parents—some offer online services and others offer weekly columns. To learn more about what your state's Parent to Parent program offers, please visit:
www.parenttoparent.org/states_p2p_progs.htm

Families & Advocates Partnership for Education (FAPE)

FAPE works with the Epilepsy Foundation to inform families about the Individuals with Disabilities Education Act of 1997 (IDEA '97) so that children with disabilities can reach their full potential. The site includes a listing of parent training and information centers and community groups in the United States.

PACER Center
8161 Normandale Boulevard
Minneapolis, MN 55437-1044
(952) 838-9000
www.fape.org

Parent Advocacy Coalition of Educational Rights (PACER)

PACER serves in Minnesota and its Web site lists PACER equivalents around the country. The mission of PACER is to expand opportunities and enhance the quality of life of children and young adults with disabilities and their families based on the concept of parents helping parents.

PACER Center
8161 Normandale Boulevard
Minneapolis, MN 55437-1044
(952) 838-9000
www.pacer.org

National Information Center for Children and Youth with Disabilities (NICHCY)

This national information and referral center provides information on disabilities and disability-related issues for families, educators, and other professionals focusing on children and youth. This site provides a list of some of the resources available in your state.

National Information Center for Children and Youth with Disabilities
P.O. Box 1492
Washington, DC 20013
(800) 695-0285
www.nichcy.org

HEATH Resource Center (a division of the American Council of Education)

Write HEATH or call its toll-free number below for information about higher education and adult training for people with disabilities.

HEATH
The George Washington University
HEATH Resource Center
2121 K street, NW Suite 220
Washington, DC 20037
(800) 544-3284
www.heath.gwu.edu

General Information Databases

MedlinePlus
<http://medlineplus.gov>

Includes extensive information from the National Institutes of Health and other trusted sources on more than 600 diseases and conditions. There are also lists of hospitals and physicians, a medical encyclopedia and dictionary, health information in Spanish, extensive information on prescription and nonprescription drugs, health information from the media, and links to thousands of clinical trials. MedlinePlus is updated daily and can be bookmarked.

healthfinder®
<http://www.healthfinder.gov>

An award-winning federal Web site developed by the U.S. Department of Health and Human Services together with other federal agencies. Since 1997, healthfinder® has been recognized as a key resource for finding the best government and nonprofit health and human services information on the Internet. healthfinder® links to carefully selected information and Web sites from more than 1,800 health-related organizations.

Resources in Spanish

healthfinder®
www.healthfinder.gov/espanol

healthfinder® es una guía gratuita a la información confiable de la salud, desarrollada por el Departamento de Salud y Servicios Humanos de los Estados Unidos (U.S. Department of Health and Human Services). Este sitio proporciona un índice de uso fácil para búsquedas sobre información de la salud, que ha sido cuidadosamente revisada y que proviene de más de 1,800 agencias gubernamentales, organizaciones sin fines de lucro y universidades.

NOAH
www.noah-health.org/spanish/spqksearch.html

New York On-Line Access to Health (NOAH) supports both English and Spanish that allows NOAH to serve the Spanish-speaking population of health consumers. "NOAH aspira proporcionarle al consumidor información sobre la salud que sea de alta calidad, oportuna, precisa, pertinente e imparcial."

