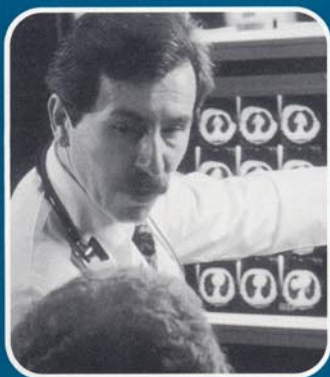


brain connections

Your Source Guide to Information on
Brain Diseases and Disorders

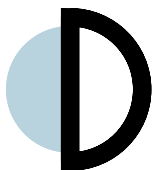
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The
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Alliance
for
Brain
Initiatives



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Fax: (212) 593-7623

E-mail: dabiinfo@dana.org

Internet site: www.dana.org

Brain Connections

*Your Source Guide to Information on
Brain Diseases and Disorders*

The brain, the most sophisticated, complex entity we know, defines us as human. Through it, we perceive the world, experience sensations, learn, reason, communicate, and relate with each other. Unfortunately, because of that very same complexity, the brain lies at the core of many of our most serious diseases and disorders. Today, one out of every five Americans suffers from a brain-related disease or disorder.

As we begin the new century, advances in our understanding of brain function and disease are enhancing the possibilities for treating and healing conditions once thought beyond help. Using the tools of modern brain science such as brain imaging, genetics, and drug development, brain scientists are bringing hope to those afflicted with a brain disease or disorder in all stages of life: during early childhood, throughout the mature years, and in aging.

This guide lists organizations that assist people with a brain-related disorder, as well as those responsible for their care and treatment. It includes more than 275 organizations, listed alphabetically by the disease or disorder that is their primary intent. To help the most readers, emphasis has been placed on organizations national in scope. Most of these groups sponsor local chapters or affiliates and make referrals to local medical professionals and organizations.

In addition to telephone numbers and mailing addresses, *Brain Connections* provides, where available, addresses for e-mail and Web sites, which organizations increasingly use to communicate with the public. To further help readers locate the materials and the assistance they need, graphic icons indicate services available from each organization.

Brain Connections is provided by the Dana Alliance for Brain Initiatives. Funded entirely by the Charles A. Dana Foundation, the Dana Alliance is a nonprofit organization of preeminent neuroscientists dedicated to furthering public understanding of the benefits of brain research. The Foundation, founded in 1950, is a nonprofit, private, philanthropic foundation with grant programs in science, health, and education.

The Dana Alliance does not fund research or make grants. For more information on the Dana Alliance for Brain Initiatives, see page 2.



About the Dana Alliance for Brain Initiatives

The Dana Alliance for Brain Initiatives is a nonprofit organization of more than 200 leading neuroscientists, including seven Nobel laureates. The Dana Alliance is committed to advancing public awareness about the progress and benefits of brain research and to disseminate information on the brain in an understandable and accessible fashion.

Supported entirely by the Charles A. Dana Foundation, the Dana Alliance does not fund research or make grants.

The European Dana Alliance for the Brain, launched in 1997 with a similar commitment and a membership of 63 European neuroscientists, now has more than 100 members, including four Nobel laureates.

The Dana Alliance was founded in 1992 at a scientific conference in Cold Spring Harbor, New York, sponsored by the Charles A. Dana Foundation. Nobel laureate James D. Watson, Ph.D., invited 30 preeminent scientists and the late Dana Foundation Chairman David Mahoney to the conference to assess progress in building public support for brain research.

Brain research has the potential to address many of the issues the nation faces in education, health care, and productivity. In economic terms alone, brain-related disorders cost the United States more than \$600 billion a year in direct and indirect costs.

Dana Alliance membership now includes neuroscientists in more than 50 subspecialties. All are dedicated to increasing the public's understanding of how brain research affects personal health and quality of life.

As part of its public outreach efforts, the Dana Alliance organizes the international Brain Awareness Week campaign, presents the award-winning *Gray Matters* series on public radio, and produces publications on the brain and brain research for the lay reader. Transcripts and Dana Alliance publications can be accessed on the Internet at www.dana.org.

The Dana Foundation's easy-to-use Web site, www.dana.org, offers the latest brain research news and information. Publications on current news in brain science can be downloaded, and the *Dana BrainWeb* offers links to the best sites on the World Wide Web about brain diseases and brain research.

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GENERAL INFORMATION/SUPPORT

Genetic Alliance

4301 Connecticut Ave., NW, Suite 404
Washington, DC 20008-2304
Voice: (800) 336-4363; Fax: (202) 966-8553
Web site: www.geneticalliance.org
E-mail: info@geneticalliance.org



American Academy of Neurology

1080 Montreal Ave.
St. Paul, MN 55116
Voice: (800) 879-1960; Fax: (651) 695-2791
Web site: www.aan.com
E-mail: aan@aan.com



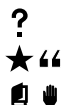
AARP

601 E Street, NW
Washington, DC 20049
Voice: (800) 424-3410
Web site: www.aarp.org
E-mail: member@aarp.org
Contact regarding membership.



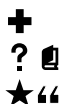
American Association of Suicidology

4201 Connecticut Avenue, NW, Suite 408
Washington, DC 20008
Voice: (202) 237-2280; Fax: (202) 237-2282
Web site: www.suicidology.org
E-mail: ajkulp0124@ix.netcom.com



American Psychiatric Association

1400 K Street, NW
Washington, DC 20005
Voice: (202) 682-6000; Fax: (202) 682-6850
Web site: www.psych.org
E-mail: apa@psych.org



American Psychological Association

750 First Street, NE
Washington, DC 20002-4242
Voice: (202) 336-5500; Fax: (202) 336-5708
Web site: www.apa.org
E-mail: publiccom@apa.org



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American Self-Help Clearinghouse

100 Hanover Ave., 2nd Fl.
Cedar Knolls, NJ 07927
Voice: (973) 326-6789; Fax: (973) 326-9467
Web site: www.selfhelpgroups.com
E-mail: ashc@cybernex.net



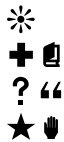
American Society for Adolescent Psychiatry

P.O. Box 520218
Dallas, TX 75357-0218
Voice: (972) 686-6166; Fax (972) 613-5532
Web site: www.adolpsych.org
E-mail: adpsych@aol.com



Easter Seals

230 W. Monroe St., Suite 1800
Chicago, IL 60606-4802
Voice: (800) 221-6827; TDD: (312) 726-4258
Fax: (312) 726-1494
Web site: www.easter-seals.org



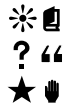
Family Caregiver Alliance

690 Market St., Suite 600
San Francisco, CA 94104
Voice: (800) 445-8106; (415) 434-3388
Fax: (415) 434-3508
Web site: www.caregiver.org
E-mail: info@caregiver.org



Federation of Families for Children's Mental Health

1101 King St., Suite 420
Alexandria, VA 22314
Voice: (703) 684-7710; Fax: (703) 836-1040
Web site: www.ffcmh.org
E-mail: ffcmh@crosslink.net



Harvard Brain Tissue Resource Center

McLean Hospital, 115 Mill St.
Belmont, MA 02478
Voice: (800) 272-4622; (617) 855-2400
Fax: (617) 855-3199
Web site: www.brainbank.mclean.org:8080
E-mail: btcr@mclean.org



Institute for Brain and Immune Disorders

914 South 8th St.
Minneapolis, MN 55404
Voice: (612) 337-8953; Fax: (612) 337-7372
Web site: www.winternet.com/~briminst
E-mail: igara001@tc.umn.edu



brain connections

National Alliance for the Mentally Ill (NAMI)

Colonial Place Three
2107 Wilson Blvd., Suite 300
Arlington, VA 22201
Voice: (800) 950-6264; Fax: (703) 524-9094
Web site: www.nami.org



National Mental Health Association

1021 Prince St.
Alexandria, VA 22314
Voice: (800) 969-6642; TTY: (800) 433-5959
Fax: (703) 684-5968
Web site: www.nmha.org
E-mail: infoctr@nmha.org



National Organization for Rare Disorders (NORD)

100 Route 37, Fairwood Professional Bldg.
P.O. Box 8923
New Fairfield, CT 06812-8923
Voice: (800) 999-6673; TDD: (203) 746-6927
Web site: www.rarediseases.org
E-mail: orphan@rarediseases.org



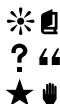
National Parent-to-Parent Support and Information Systems

P.O. Box 907
Blue Ridge, GA 30513
Voice: (800) 651-1151; Fax: (706) 374-3826
Web site: www.nppsis.org
E-mail: nppsis@ellijay.com



Well Spouse Foundation

30 E. 40th St., Suite PH
New York, NY 10016
Voice: (800) 838-0879; Fax: (212) 685-8676
Web site: www.wellspouse.org
E-mail: wellspouse@aol.com



GOVERNMENT RESOURCES

National Cancer Institute/Cancer Information Service

31 Center Dr., Building 31, MSC 2580
Bethesda, MD 20892
Voice: (800) 422-6237; TTY: (800) 332-8615
Web site: www.nci.nih.gov



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National Center for Complementary and Alternative Medicine

Information Clearinghouse

P.O. Box 8218

Silver Spring, MD 20907-8218

Voice: (888) 644-6226; TTY/TDY: (888) 644-6226

Fax: (301) 495-4957

Web site: www.nih.gov

E-mail: nccam-info@nccam.nih.gov



National Eye Institute

2020 Vision Pl.

Bethesda, MD 20892-3655

Voice: (301) 496-5248

Web site: www.nei.nih.gov

E-mail: 2020@nei.nih.gov



National Heart, Lung and Blood Institute

31 Center Dr., MSC 2480, Rm. 4A21

Bethesda, MD 20892-2480

Voice: (301) 496-4236

Web site: www.nhlbi.nih.gov



National Institute on Aging

Building 31, Rm. 5C27, 31 Center Dr.

Bethesda, MD 20892-2292

Voice: (800) 222-2225

Web site: www.nih.gov/nia

E-mail: niaic@jbs1.com



National Institute on Alcohol Abuse and Alcoholism

6000 Executive Blvd., Willco Building

Bethesda, MD 20892-7003

Voice: (301) 443-3860

Web site: www.niaaa.nih.gov



National Institute of Allergy and Infectious Diseases

Building 31, Rm. 7A-50, 31 Center Dr., MSC 2520

Bethesda, MD 20892

Voice: (301) 496-5717

Web site: www.niaid.nih.gov



National Institute of Child Health and Human Development

Building 31, Rm. 2A32, MSC 2425, 31 Center Dr.

Bethesda, MD 20892-2425

Voice: (800) 370-2943

Web site: www.nichd.nih.gov



brain connections

National Institute on Deafness and Other Communication Disorders

One Communication Ave.
Bethesda, MD 20892-3456
Voice: (800) 241-1044; TTY: (800) 241-1055
Fax: (301) 907-8830
Web site: www.nih.gov/nidcd
E-mail: nidcd@aerie.com



National Institute on Drug Abuse

6001 Executive Blvd., Rm. 5274, MSC 9581
Bethesda, MD 20892-9581
Voice: (800) 729-6686
Web site: www.nida.nih.gov



National Institute of Mental Health

Public Inquiries
6001 Executive Blvd., Rm. 8184, MSC 9663
Bethesda, MD 20892-9663
Voice: (301) 443-4513
Web site: www.nimh.nih.gov
E-mail: nimhinfo@nih.gov



National Institute of Neurological Disorders and Stroke

Office of Communications and Public Liaison
P.O. Box 5801
Bethesda, MD 20824
Voice: (800) 352-9424; (301) 496-5751
Web site: www.ninds.nih.gov



Office of Rare Diseases/National Institutes of Health

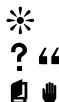
31 Center Dr., MSC 2084, Room 1B19
Bethesda, MD 20892-2084
Voice: (301) 402-4336; Fax: (301) 480-9655
Web site: www.rarediseases.info.nih.gov/ord
E-mail: HH70F@nih.gov



ACOUSTIC NEUROMA

Acoustic Neuroma Association

P.O. Box 12402
Atlanta, GA 30355
Voice: (404) 237-8023; Fax: (404) 237-2704
Web site: www.anausa.org
E-mail: ANAUUSA@aol.com



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AGENESIS CORPUS CALLOSUM

The ACC Network

University of Maine
5749 Merrill Hall, Rm. 18
Orono, ME 04469-5749
Voice: (207) 581-3119; Fax: (207) 581-3120
E-mail: um-acc@maine.edu



AGING-RELATED DISEASES

Alliance for Aging Research

2021 K Street, NW, Suite 305
Washington, DC 20006
Voice: (202) 293-2856; Fax: (202) 785-8574
Web site: www.agingresearch.org
E-mail: info@agingresearch.org



National Council on Aging

409 Third Street, SW, Suite 200
Washington, DC 20024
Voice: (202) 479-1200; Fax: (202) 479-0735
Web site: www.ncoa.org
E-mail: info@ncoa.org



National Institute on Aging

(See p. 8.)

AIDS DEMENTIA

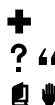
CDC National Prevention Information Network

P.O. Box 6003
Rockville, MD 20849-6003
Voice: (800) 458-5231; TTY: (800) 243-7012
Fax: (888) 282-7681
Web site: www.cdcpin.org
E-mail: info@cdcpin.org



Gay Men's Health Crisis (GMHC)

119 W. 24th St.
New York, NY 10011
Voice: (800) 243-7692; (212) 367-1000
Web site: www.gmhc.org



National Institute of Allergy and Infectious Diseases

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ALCOHOL AND DRUG ABUSE (See also: Drug Abuse)

Al-Anon Family Groups

1600 Corporate Landing Parkway
Virginia Beach, VA 23454
Voice: (757) 563-1600; Fax: (757) 563-1655
Web site: www.al-anon.alateen.org



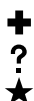
Alcoholics Anonymous

A.A. World Services, Inc.
475 Riverside Dr., 11th Fl.
New York, NY 10155
Voice: (212) 870-3400; Fax: (212) 870-3003
Web site: www.aa.org



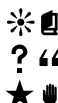
American Society of Addiction Medicine

4601 North Park Ave., Suite 101, Upper Arcade
Chevy Chase, MD 20815
Voice: (301) 656-3920; Fax: (301) 656-3815
Web site: www.asam.org
E-mail: email@asam.org



Betty Ford Center at Eisenhower

39000 Bob Hope Dr.
Rancho Mirage, CA 92270
Voice: (800) 854-9211
Web site: www.bettyfordcenter.org
E-mail: admissions@bettyfordcenter.org



National Clearinghouse for Alcohol & Drug Information

P.O. Box 2345
Rockville, MD 20847-2345
Voice: (800) 729-6686; Fax: (301) 468-6433
Web site: www.health.org
E-mail: info@health.org



National Council on Alcoholism and Drug Dependence (NCADD)

12 W. 21st St.
New York, NY 10010
Voice: (800) 622-2255; Fax: (212) 645-1690
Web site: www.ncadd.org
E-mail: national@ncadd.org



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Recovery, Inc.

802 N. Dearborn St.
Chicago, IL 60610
Voice: (312) 337-5661; Fax: (312) 337-5756
Web site: www.recovery-inc.com
E-mail: inquiry@recovery-inc.com



National Institute on Alcohol Abuse and Alcoholism

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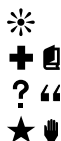
National Institute on Drug Abuse

(See p. 9.)

ALZHEIMER'S DISEASE
(See also: Aging-Related Diseases)

Alzheimer's Association

919 N. Michigan Ave., Suite 1100
Chicago, IL 60611
Voice: (800) 272-3900; Fax: (312) 335-1110
Web site: www.alz.org



**Alzheimer's Disease Education and Referral Center
National Institute on Aging**

P.O. Box 8250
Silver Spring, MD 20907-8250
Voice: (800) 438-4380; Fax: (301) 495-3334
Web site: www.alzheimers.org
E-mail: adear@alzheimers.org



National Institute on Aging

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AMYOTROPHIC LATERAL SCLEROSIS
(ALS or LOU GEHRIG'S DISEASE)

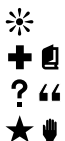
The ALS Association

27001 Agoura Rd., Suite 150
Calabasas Hills, CA 91301-5104
Voice: (800) 782-4747; Fax: (818) 880-9006
Web site: www.alsa.org
E-mail: alsinfo@alsa-national.org



Les Turner ALS Foundation

8142 N. Lawndale Ave.
Skokie, IL 60076
Voice: (888) 257-1107; Fax: (847) 697-9109
Web site: www.lesturnerals.org
E-mail: info@lesturnerals.org



brain connections

ANGELMAN SYNDROME (See: Rare Disorders)

ANXIETY DISORDERS

Anxiety Disorders Association of America

11900 Parklawn Dr., Suite 100
Rockville, MD 20852-2624
Voice: (301) 231-9350; Fax: (301) 231-7392
Web site: www.adaa.org
E-mail: anxdis@adaa.org



Anxiety Disorder Education Program Library

National Institute of Mental Health
Voice: (888) 826-9438
Web site: www.nimh.gov/anxiety/index.htm



Freedom From Fear

308 Seaview Ave.
Staten Island, NY 10305
Voice: (718) 351-1717;
(888) 442-2022 (for medical referrals)
Fax: (718) 667-8893
Web site: www.freedomfromfear.org
E-mail: ffnadsd@aol.com



National Anxiety Foundation

3135 Custer Dr.
Lexington, KY 40517
(Write for information only.)
Web site: www.lexington-on-line.com/naf.html



APHASIA

National Aphasia Association

156 Fifth Ave., Suite 707
New York, NY 10010
Voice: (800) 922-4622
Web site: www.aphasia.org



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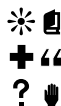
 volunteer opportunities



ATAXIA AND ATAXIA-TELANGIECTASIA (See also: Rare Disorders)

A-T Children's Project

668 S. Military Trail
Deerfield Beach, FL 33442
Voice: (800) 543-5728; Fax: (954) 725-1153
Web site: www.atcp.org
E-mail: Jennifer@atcp.org



National Ataxia Foundation

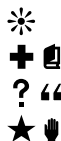
2600 Fernbrook Lane, #119
Minneapolis, MN 55447
Voice: (763) 553-0020; Fax: (763) 553-0167
Web site: www.ataxia.org
E-mail: naf@ataxia.org



ATTENTION DEFICIT/HYPERACTIVITY DISORDER (ADHD) (See also: Learning Disabilities)

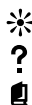
Children and Adults With Attention Deficit/ Hyperactivity Disorder (CH.A.D.D)

8181 Professional Pl., Suite 201
Landover, MD 20785
Voice: (800) 233-4050; Fax: (301) 306-7090
Web site: www.chadd.org
E-mail: national@chadd.org



National ADD Association

1788 Second St., Suite 200
Highland Park, IL 60035
Voice: (847) 432-2332; Fax: (847) 432-5874
Web site: www.add.org
E-mail: mail@add.org



AUTISM

Autism Genetic Resource Exchange

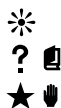
5225 Wilshire Blvd., Suite 226
Los Angeles, CA 90036
Voice: (888) 288-4762; Fax: (831) 684-0240
Web site: www.agre.org
E-mail: familyagre@agre.org



brain connections

Autism Society of America

7910 Woodmont Ave., Suite 300
Bethesda, MD 20814-3015
Voice: (800) 328-8476; Fax: (301) 657-0869
Web site: www.autism-society.org



Cure Autism Now Foundation

5455 Wilshire Blvd., Suite 715
Los Angeles, CA 90036
Voice: (323) 549-0500; Fax: (323) 549-0547
Web site: www.cureautismnow.org
E-mail: CAN@Primenet.com



National Alliance for Autism Research

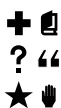
414 Wall St.
Princeton, NJ 08540
Voice: (888) 777-6227; Fax: (609) 430-9163
Web site: www.naar.org
E-mail: naar@naar.org



AUTOIMMUNE DISEASES

American Autoimmune Related Diseases Association

22100 Gratiot Ave.
East Detroit, MI 48021
Voice: (810) 776-3900; Fax: (810) 776-3903
Web site: www.aarda.org
E-mail: aarda@aol.com



National Institute of Allergy and Infectious Diseases

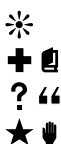
(See p. 8.)

BACK PAIN (See: Pain, Chronic; Spine-Related Injury)

BATTEN DISEASE

Batten Disease Support and Research Association

120 Humphries Dr., Suite 2
Reynoldsburg, OH 43068
Voice: (800) 448-4570
Web site: www.bdsra.org
E-mail: bdsra1@bdsra.org



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BEHAVIOR THERAPY

Association for Advancement of Behavior Therapy (AABT)

305 Seventh Ave., Suite 1601

New York, NY 10001

Voice: (212) 647-1890; Fax: (212) 647-1865

Web site: www.aabt.org

E-mail: referral@aabt.org



BEHCET'S DISEASE

American Behcet's Disease Association

P.O. Box 280240

Memphis, TN 38168-0240

Voice: (800) 723-4238

Web site: www.pweb.netcom.com/~mharting



BENIGN ESSENTIAL BLEPHAROSPASM

Benign Essential Blepharospasm Research Foundation

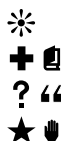
P.O. Box 12468

Beaumont, TX 77726-2468

Voice: (409) 832-0788; Fax: (409) 832-0890

Web site: www.blepharospasm.org

E-mail: bebrf@ih2000.net



BIRTH DEFECTS

Birth Defect Research for Children

930 Woodcock Rd., Suite 225

Orlando, FL 32803

Voice: (407) 245-7035; Fax: (407) 895-0824

Web site: www.birthdefects.org

E-mail: abdc@birthdefects.org



March of Dimes Birth Defects Foundation

1275 Mamaroneck Ave.

White Plains, NY 10605

Voice: (888) 663-4637; Fax: (914) 997-4763

Web site: www.modimes.org

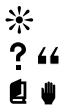


brain connections

BLINDNESS/VISION IMPAIRMENT

Helen Keller National Center for Deaf/Blind Youth and Adults

111 Middle Neck Rd.
Sands Point, NY 11050
Voice: (516) 944-8900; TTY: (516) 944-8637
Fax: (516) 944-7302
Web site: www.helenkeller.org/national
E-mail: hknkdir@aol.com



Lighthouse International

111 E. 59th St.
New York, NY 10022
Voice: (212) 821-9200; TDD: (212) 821-9713
Fax: (212) 821-9707
Web site: www.lighthouse.org
E-mail: info@lighthouse.org



Prevent Blindness America

500 E. Remington Rd.
Schaumburg, IL 60173
Voice: (800) 331-2020; Fax: (847) 843-8458
Web site: www.preventblindness.org



Research to Prevent Blindness

645 Madison Ave., 21st Fl.
New York, NY 10022
Voice: (800) 621-0026; Fax: (212) 688-6231
Web site: www.rpbusa.org
E-mail: info@rpbusa.org



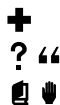
National Eye Institute

(See p. 8.)

BORDERLINE PERSONALITY DISORDER

Treatment and Research Advancements Association for Personality Disorders (TARA/APD)

23 Greene St.
New York, NY 10013
Voice: (888) 482-7227; Fax: (212) 966-6895
Web site: www.TARAforBPD.org
E-mail: TARAforBPD@aol.com



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BRAIN INJURY/PREVENTION (See also: Head Injury/Trauma)

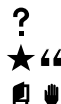
Brain Injury Association

105 N. Alfred St.
Alexandria, VA 22314
Voice: (800) 444-6443; Fax: (703) 236-6001
Web site: www.biausa.org
E-mail: FamilyHelpline@biausa.org



Brain Injury Services

10340 Democracy Lane, Suite 305
Fairfax, VA 22030
Voice: (703) 352-1656; TDD: (800) 828-1120
Fax: (703) 385-6915
Web site: www.braininjurysvcs.org
E-mail: kluffred@braininjurysvcs.org



Think First Foundation

5550 Meadowbrook Dr., Suite 110
Rolling Meadows, IL 60008
Voice: (800) 844-6556; Fax: (847) 890-9005
Web site: www.thinkfirst.org
E-mail: thinkfirst@thinkfirst.org



BRAIN TUMOR (See also: Pediatric Brain Tumor; Pituitary Disorders)

American Brain Tumor Association

2720 River Rd., Suite 146
Des Plaines, IL 60018
Voice: (800) 886-2282; Fax: (847) 827-9918
Web site: www.abta.org
E-mail: info@abta.org



The Brain Tumor Society

124 Watertown St., Suite 3-H
Watertown, MA 02472
Voice: (800) 770-8287; Fax: (617) 924-9998
Web site: www.tbts.org
E-mail: info@tbts.org



Dana-Farber Cancer Institute

44 Binney St.
Boston, MA 02115
Voice (Adult Care): (800) 320-0022
Voice (Pediatric Care): (866) 733-4662
Web site: www.dana-farber.net



brain connections

The Healing Exchange BRAIN TRUST

MIT-Kendall 425743

Cambridge, MA 02142-0014

Voice: (617) 876-2002; Fax: (617) 623-2203

Web site: www.braintrust.org

E-mail: info@braintrust.org



National Brain Tumor Foundation

414 13th St., Suite 700

Oakland, CA 94612-2603

Voice: (800) 934-2873; Fax: (510) 839-9779

Web site: www.braintumor.org

E-mail: nbtf@braintumor.org



CEREBRAL PALSY

United Cerebral Palsy (UCP)/United Cerebral Palsy Research and Education Foundation

1660 L Street, NW, Suite 700

Washington, DC 20036-5602

Voice: (800) 872-5827; Fax: (202) 776-0414

Web site: www.ucp.org

E-mail: ucpnapl@ucp.org



CHARCOT-MARIE-TOOTH DISEASE

Charcot-Marie-Tooth Association

2700 Chestnut St.

Chester, PA 19013

Voice: (800) 606-2682; Fax: (610) 499-9267

Web site: www.charcot-marie-tooth.org

E-mail: CMTASSOC@aol.com



CHIARI MALFORMATION

(See: Spina Bifida; Syringomyelia)

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COMA (See also: Brain Injury/Prevention; Head Injury/Trauma)

Coma Recovery Association

100 E. Old Country Rd., Suite 9

Mineola, NY 11501

Voice: (516) 997-1826; Fax: (516) 746-7706

Web site: www.comarecovery.org

E-mail: office@comarecovery.org



CONCUSSION (See: Head Injury/Trauma)

DEAFNESS/HEARING LOSS

Alexander Graham Bell Association for the Deaf and Hard of Hearing

3417 Volta Place, NW

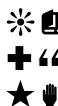
Washington, DC 20007

Voice: (202) 337-5220

TDD: (202) 337-5220; Fax: (202) 337-8314

Web site: www.agbell.org

E-mail: agbell2@aol.com



American Society for Deaf Children

P.O. Box 3355

Gettysburg, PA 17325

Voice: (800) 942-2732; TTY: (717) 334-7922

Fax: (717) 334-8808

Web site: www.deafchildren.org

E-mail: asdc1@aol.com



Better Hearing Institute

515 King St., Suite 420

Alexandria, VA 22314

Voice: (800) 327-9355; Fax: (703) 684-3393

Web site: www.betterhearing.org

E-mail: mail@betterhearing.org



Boys Town National Research Hospital

555 N. 30th St.

Omaha, NE 68131

Voice: (402) 498-6749

Website: www.boystown.org/btnrh

E-mail: btnrh-info@boystown.org



Cochlear Implant Association International

5335 Wisconsin Ave., Suite 440

Washington, DC 20015-2034

Voice: (202) 895-2781; Fax: (202) 895-2782

Web site: www.cici.org



brain connections

Laurent Clerc National Deaf Education Center at Gallaudet University

800 Florida Ave., NE
Washington, DC 20002
TTY/Voice: (202) 651-5340
Web site: <http://www.gallaudet.edu>
(For ages 0-21)



National Cued Speech Association

4245 East Ave.
Rochester, NY 14618
Voice: (716) 389-2776; Fax: (716) 586-2452
Web site: www.cuedspeech.org



Self Help for Hard of Hearing People

7910 Woodmont Ave., Suite 1200
Bethesda, MD 20814
Voice: (301) 657-2248
TTY: (301) 657-2249; Fax: (301) 913-9413
Web site: www.shhh.org
E-mail: national@shhh.org



National Institute on Deafness and Other Communication Disorders Information Clearinghouse (See p. 9.)

DEJERINE-SOTTAS DISEASE

Muscular Dystrophy Association

(See p. 31.)

DEPRESSION/MANIC DEPRESSION

Depression and Related Affective Disorders Association (DRADA)

Meyer 3-181, 600 N. Wolfe St.
Baltimore, MD 21287-7381
Voice: (410) 955-4647; Fax: (410) 614-3241
Web site: www.med.jhu.edu/drada
E-mail: drada@jhmi.edu



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National Alliance for Research on Schizophrenia and Depression (NARSAD)

60 Cutter Mill Rd., Suite 404
Great Neck, NY 11021
Voice: (800) 829-8289; Fax: (516) 487-6930
Web site: www.narsad.org



National Depressive and Manic-Depressive Association

730 N. Franklin, #501
Chicago, IL 60610
Voice: (800) 826-3632; Fax: (312) 642-7243
Web site: www.ndmda.org
E-mail: myrtis@aol.com



National Foundation for Depressive Illness

P.O. Box 2257
New York, NY 10116
Voice: (800) 239-1265
Web site: www.depression.org



On Our Own

P.O. Box 18899
Baltimore, MD 21206
Voice: (410) 444-4500; Fax: (410) 444-8755
E-mail: ONOUROWN@aol.com



National Institute of Mental Health

(See p. 9.)

DISABILITY AND REHABILITATION
(See also: Paralysis)

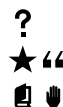
Disabled Sports USA

451 Hungerford Dr., Suite 100
Rockville, MD 20850
Voice: (301) 217-0960; Fax: (301) 217-0968
Web site: www.dsusa.org
E-mail: dsusa@dsusa.org



Goodwill Industries International

9200 Rockville Pike
Bethesda, MD 20814
Voice: (800) 741-0186; TDD: (301) 530-9759
Fax: (301) 530-1516
Web site: www.goodwill.org
E-mail: info@goodwill.org



brain connections

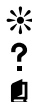
HEATH Resource Center

One Dupont Circle, NW, Suite 800
Washington, DC 20036-1193
Voice: (202) 939-9320; Voice/TTY: (800) 544-3284
Fax: (202) 833-4760
Web site: www.heath-resource-center.org
E-mail: HEATH@ace.nche.edu



National Information Center for Children & Youth With Disabilities

P.O. Box 1492
Washington, DC 20013-1492
Voice: (800) 695-0285
Voice/TTY: (800) 695-0285; Fax: (202) 884-8441
Web site: www.nichcy.org
E-mail: nichcy@aed.org



National Rehabilitation Information Center (NARIC)

1010 Wayne Ave., Suite 800
Silver Spring, MD 20910-3319
Voice: (800) 346-2742; TDD: (301) 495-5626
Fax: (301) 562-2401
Web site: www.naric.com/naric

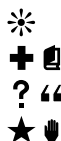


DIZZINESS (See: Vestibular Disorders)

DOWN SYNDROME

National Down Syndrome Society

666 Broadway, Suite 810
New York, NY 10012-2317
Voice: (800) 221-4602; Fax: (212) 979-2873
Web site: www.ndss.org
E-mail: info@ndss.org



DRUG ABUSE (See also: Alcohol and Drug Abuse)

Do It Now Foundation

P.O. Box 27568
Tempe, AZ 85285
Voice: (408) 736-0599; Fax: (408) 736-0771
Web site: www.doitnow.org
E-mail: doitnow@cbazillion.com



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National Families in Action

2957 Clairmont Rd., NE
Atlanta, GA 30329
Voice: (404) 248-9676; Fax: (404) 248-1312
Web site: www.nationalfamilies.org



Phoenix House

164 W. 74th St.
New York, NY 10023
Voice: (800) 378-4435; Fax: (212) 496-6035
Web site: www.phoenixhouse.org
E-mail: phcomm@phoenixhouse.org



National Institute on Drug Abuse

(See p. 9.)

DYSAUTONOMIA

The Dysautonomia Foundation

633 Third Ave., 12th Fl.
New York, NY 10017
Voice: (212) 949-6644; Fax: (212) 682-7625
Web site: www.med.nyu.edu/fd/fdcenter.html



DYSLEXIA (See also: Learning Disabilities)

The International Dyslexia Association

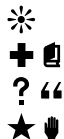
8600 LaSalle Rd., Chester Bldg., Suite 382
Baltimore, MD 21286-2044
Voice: (800) 222-3123; Fax: (410) 321-5069
Web site: www.interdys.org
E-mail: info@interdys.org



DYSTONIA (See also: Tardive Dyskinesia/Tardive Dystonia)

Dystonia Medical Research Foundation

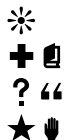
One E. Wacker Dr., Suite 2430
Chicago, IL 60601-1905
Voice: (800) 377-3978; Fax: (312) 803-0138
Web site: www.dystonia-foundation.org
E-mail: dystonia@dystonia-foundation.org



EATING DISORDERS

American Anorexia/Bulimia Association

165 W. 46th St., Suite 1108
New York, NY 10036
Voice: (212) 575-6200; Fax: (212) 278-0698
Web site: www.aabainc.org
E-mail: info@aabainc.org



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Anorexia Nervosa and Related Eating Disorders (ANRED)

P.O. Box 5102
Eugene, OR 97405
Voice: (800) 931-2237
Web site: www.anred.com



National Association of Anorexia Nervosa and Associated Disorders (ANAD)

P.O. Box 7
Highland Park, IL 60035
Voice: (847) 831-3438; Fax: (847) 433-4632
Web site: www.anad.org
E-mail: anad20@aol.com

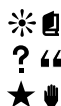


ENCEPHALITIS, RASMUSSEN'S (See: Autoimmune Diseases)

EPILEPSY

Epilepsy Foundation

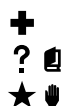
4351 Garden City Dr.
Landover, MD 20785
Voice: (800) 332-1000; Fax: (301) 577-2684
Web site: www.efa.org
E-mail: postmaster@efa.org



ESSENTIAL TREMOR/FAMILIAL TREMOR

International Tremor Foundation

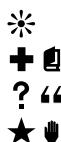
7046 W. 105th St.
Oveland Park, KS 66212-1803
Voice: (913) 341-3880; Fax: (913) 341-1296
Web site: www.essentialtremor.org
E-mail: IntTremorFnd@worldnet.att.net



FETAL ALCOHOL SYNDROME

National Organization on Fetal Alcohol Syndrome

216 G Street, NE
Washington, DC 20002
Voice: (800) 666-6327; Fax: (202) 466-6456
Web site: www.nofas.org
E-mail: NOFAS@erols.com



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National Institute of Child Health and Human Development

(See p. 8.)

National Institute on Alcohol Abuse and Alcoholism

(See p. 8.)

FRAGILE X SYNDROME

FRAXA Research Foundation

45 Pleasant St.

Newburyport, MA 01950

Voice: (978) 462-1866; Fax: (978) 463-9985

Web site: www.fraxa.org

E-mail: info@fraxa.org



FRIEDREICH'S ATAXIA

Muscular Dystrophy Association

(See p. 31.)

GAUCHER'S DISEASE

National Gaucher Foundation

11140 Rockville Pike, Suite 350

Rockville, MD 20852-3106

Voice: (800) 925-8885; Fax: (301) 816-1516

Web site: www.gaucherdisease.org

E-mail: ngf@gaucherdisease.org



GUILLAIN-BARRE SYNDROME

Guillain-Barre Syndrome Foundation International

P.O. Box 262

Wynnewood, PA 19096

Voice: (610) 667-0131; Fax: (610) 667-7036

Web site: www.webmast.com/gbs

E-mail: gbint@ix.netcom.com



HEADACHE

American Council for Headache Education

19 Mantua Rd.

Mt. Royal, NJ 08061

Voice: (856) 423-0258; Fax: (856) 423-0082

Web site: www.achenet.org

E-mail: achhq@talley.com



brain connections

Association for Applied Psychophysiology and Biofeedback

10200 W. 44th Ave., Suite 304
Wheat Ridge, CO 80033-2840
Voice: (800) 477-8892; Fax: (303) 422-8894
Web site: www.aapb.org
E-mail: aapb@resourcenter.com



National Headache Foundation

428 W. St. James Pl., 2nd Fl.
Chicago, IL 60614-2750
Voice: (888) 643-5552; Fax: (773) 525-7357
Web site: www.headaches.org
E-mail: info@headaches.org



HEAD INJURY/TRAUMA (See also: Brain Injury/Prevention; Coma)

Brain Trauma Foundation

523 E. 72nd St., 8th Fl.
New York, NY 10021
Voice: (212) 772-0608; Fax: (212) 772-0357
Web site: www.braintrauma.org
E-mail: soraya@braintrauma.org



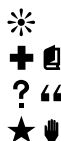
Head Injury Hotline

212 Pioneer Bldg.
Seattle, WA 98104-2221
Voice: (206) 621-8558; Fax: (206) 624-4961
Web site: www.headinjury.com
E-mail: brain@headinjury.com



Brain Injury Association/Family Help Line

105 N. Alfred St.
Alexandria, VA 22314
Voice: (800) 444-6443; Fax: (703) 236-6001
Web site: www.biausa.org
E-mail: advocacy@biausa.org



Rehabilitation Research Center for Traumatic Brain & Spinal Cord Injury

950 S. Bason Ave., Suite 2011
San Jose, CA 95128
Voice: (800) 352-1956; Fax: (408) 295-9913
Web site: www.tbi-sci.org
E-mail: tbisci@tbi-sci.org



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HUNTINGTON'S DISEASE

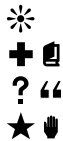
Hereditary Disease Foundation

11400 W. Olympic Blvd., Suite 855
Los Angeles, CA 90064
Voice: (310) 575-9656; Fax: (310) 575-9156
Web site: www.hdfoundation.org
E-mail: cures@hdfoundation.org



Huntington's Disease Society of America

158 W. 29th St., 7th Fl.
New York, NY 10001
Voice: (800) 345-4372; Fax: (212) 239-3430
Web site: www.hdsa.org
E-mail: hdsainfo@hdsa.org



HYDROCEPHALUS

Guardians of Hydrocephalus Research Foundation

2618 Avenue Z
Brooklyn, NY 11235
Voice: (800) 458-8655; Fax: (718) 743-1171
E-mail: ghrf2618@aol.com



Hydrocephalus Association

875 Market St., Suite 705
San Francisco, CA 94102
Voice: (415) 732-7040; Fax: (415) 732-7044
Web site: www.hydroassoc.org
E-mail: hydroassoc@aol.com



National Hydrocephalus Foundation

12413 Centralia Rd.
Lakewood, CA 90715
Voice: (888) 260-1789; Fax: (562) 924-6666
Web site: www.nhfonline.org
E-mail: debbifields@nhfonline.org



JOSEPH DISEASES (See: Rare Disorders)

JOUBERT SYNDROME

The Joubert Syndrome Foundation

12348 Summer Meadow Rd.
Rock, MI 49880
Voice: (906) 359-4707
Web site: www.joubertfoundation.com
E-mail: email@joubertfoundation.com



brain connections

LEARNING DISABILITIES

Learning Disabilities Association of America

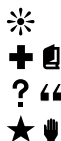
4156 Library Rd.

Pittsburgh, PA 15234

Voice: (888) 300-6710; Fax: (412) 344-0224

Web site: www.ldaamerica.org

E-mail: ldanatl@usaor.net



Learning Disabilities Network

72 Sharp St., Suite A-2

Hingham, MA 02043

Voice: (781) 340-5605; Fax: (781) 340-5603



National Center for Learning Disabilities

381 Park Ave., South, Suite 1401

New York, NY 10016

Voice: (888) 575-7373; Fax: (212) 545-9665

Web site: www.nclld.org



The International Dyslexia Association

(See p. 24.)

LEIGH'S DISEASE (See: Rare Disorders)

LEUKODYSTROPHY

United Leukodystrophy Foundation

2304 Highland Dr.

Sycamore, IL 60178

Voice: (800) 728-5483; Fax: (815) 895-2432

Web site: www.ulf.org

E-mail: ulf@tbcnet.com



LOWE SYNDROME

Low Syndrome Association

222 Lincoln St.

West Lafayette, IN 47906

Voice: (765) 743-3634

Web site: www.lowesyndrome.org

E-mail: info@lowesyndrome.org



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LUPUS

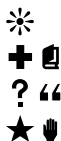
Lupus Foundation of America

1300 Piccard Dr., Suite 200
Rockville, MD 20850

Voice: (800) 558-0121; Fax: (301) 670-9486

Web site: www.lupus.org

E-mail: lupusinfo@aol.com



MACHADO-JOSEPH DISEASES (See: Rare Disorders)

MEIGE SYNDROME (See: Benign Essential Blepharospasm)

MENTAL RETARDATION

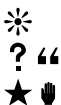
The Arc of the United States

1010 Wayne Ave., Suite 650
Silver Spring, MD 20910

Voice: (800) 433-5255; Fax: (301) 565-5342

Web site: www.thearc.org

E-mail: info@thearc.org



MOEBIUS SYNDROME (See: Rare Disorders)

MULTIPLE SCLEROSIS

Multiple Sclerosis Association of America

706 Haddonfield Rd.
Cherry Hill, NJ 08002

Voice: (800) 532-7667

Web site: www.msaa.com

E-mail: msaa@msaa.com



Multiple Sclerosis Foundation

6350 N. Andrews Ave.
Fort Lauderdale, FL 33309

Voice: (800) 441-7055; Fax: (954) 351-0630

Web site: www.msfacts.org

E-mail: support@msfacts.org



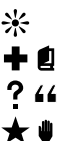
National Multiple Sclerosis Society

733 Third Ave., 6th Fl.
New York, NY 10017

Voice: (800) 344-4867; Fax: (212) 986-7981

Web site: www.nmss.org

E-mail: NAT@nmss.org



brain connections

MUSCULAR DYSTROPHY

Muscular Dystrophy Association

3300 E. Sunrise Dr.

Tucson, AZ 85718

Voice: (800) 572-1717; Fax: (520) 529-5300

Web site: www.mdausa.org

E-mail: mda@mdausa.org



MYASTHENIA GRAVIS

Myasthenia Gravis Foundation of America

123 W. Madison St., Suite 800

Chicago, IL 60602

Voice: (800) 541-5454; Fax: (312) 853-0523

Web site: www.myasthenia.org

E-mail: myastheniagravis@msn.com



Muscular Dystrophy Association

(See above.)

MYOSITIS

Myositis Association of America

755 Cantrell Ave., Suite C

Harrisonburg, VA 22801

Voice: (800) 821-7356; Fax: (540) 432-0206

Web site: www.myositis.org

E-mail: MAA@myositis.org



NARCOLEPSY (See also: Sleep Disorders)

Narcolepsy Network

10921 Reed Hartman Hwy.

Cincinnati, OH 45242

Voice: (513) 891-3522; Fax: (513) 891-3836

Web site: www.narcolepsynetwork.org

E-mail: narnet@aol.com



NEIMANN-PICK DISEASE (See: Rare Disorders)

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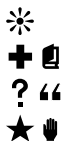
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NEUROFIBROMATOSIS

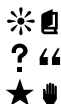
National Neurofibromatosis Foundation

95 Pine St., 16th Fl.
New York, NY 10005
Tel: (800) 323-7938; Fax: (212) 747-0004
Web site: www.nf.org
E-mail: nnff@nf.org



Neurofibromatosis, Inc.

8855 Annapolis Rd., Suite 110
Lanham, MD 20706-2924
Voice: (800) 942-6825; Fax: (301) 577-0016
Web site: www.nfinc.org
E-mail: NfInc@aol.com



NEUROMUSCULAR DISEASES

(See also: Polio/Post-Polio Syndrome;
Charcot-Marie-Tooth Syndrome)

International Ventilator Users Network/Gazette International Networking Institute (GINI)

4207 Lindell Blvd., Suite 110
St. Louis, MO 63108
Voice: (314) 534-0475; TDD: (800) 735-2966, 2466 (V)
Fax: (314) 534-5070
Web site: www.post-polio.org
E-mail: gini_intl@msn.com



Muscular Dystrophy Association

(See p. 31.)

NEUROVASCULAR DISEASES

(See also: Stroke, Epilepsy, Brain Tumor)

Barrow Neurological Institute at St. Joseph's Hospital and Medical Center

350 W. Thomas Rd.
Phoenix, AZ 85013
Voice: (602) 406-3000
Web site: www.thebni.com



OBSESSIVE-COMPULSIVE DISORDER (OCD)

Obsessive-Compulsive Foundation

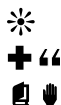
337 Notch Hill Rd.
North Branford, CT 06471
Voice: (203) 315-2190; Fax: (203) 315-2196
Web site: www.ocfoundation.org
E-mail: info@ocfoundation.org



brain connections

Trichotillomania Learning Center

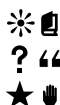
1215 Mission St., Suite 2
Santa Cruz, CA 95060
Voice: (831) 457-1004; Fax: (831) 426-4383
Web site: www.trich.org
E-mail: trichster@aol.com



PAIN (CHRONIC)

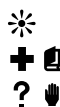
American Chronic Pain Association

P.O. Box 850
Rocklin, CA 95677
Voice: (916) 632-0922; Fax: (916) 632-3208
Web site: www.theacpa.org
E-mail: ACPA@pacbell.net



National Chronic Pain Outreach Association

P.O. Box 274
Millboro, VA 24460
Voice: (540) 862-9437; Fax: (540) 862-9485
Web site: www.chronicpain.org
E-mail: ncpoa@cfw.com

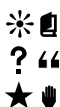


PANIC DISORDERS (See: Anxiety Disorders)

PARALYSIS (See also: Disability and Rehabilitation; Spinal Cord Injury)

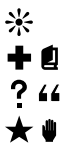
Kent Waldrep National Paralysis Foundation

16415 Addison Rd., Suite 550
Addison, TX 75001
Voice: (800) 925-2873; Fax: (972) 248-7313
Web site: www.kwnpf.org
E-mail: kwnpf@kwnpf.org



The Miami Project to Cure Paralysis

P.O. Box 016960, Mail Locator R-48
Miami, FL 33101
Voice: (800) 782-6387; Fax: (305) 243-6017
Web site: www.miamiproject.miami.edu
E-mail: mpinfo@miamiproj.med.miami.edu



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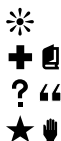
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Paralyzed Veterans of America

801 18th St., NW
Washington, DC 20006
Voice: (800) 424-8200; Fax: (202) 223-0851
Web site: www.pva.org
E-mail: info@pva.org



PARKINSON'S DISEASE

American Parkinson Disease Association

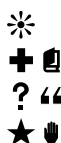
345 E. 37th St., Suite 317C
New York, NY 10016
Voice: (888) 400-2732; Fax: (212) 983-1387
Web site: www.apdaparkinson.com
E-mail: info@apdaparkinson.com



12256

The National Parkinson Foundation

1501 NW Ninth Ave.
Miami, FL 33136
Voice: (800) 327-4545; Fax: (305) 243-4403
Web site: www.parkinson.org
E-mail: mailbox@npfmed.miami.edu



Michael J. Fox Foundation for Parkinson's Research

840 Third St.
Santa Rosa, CA 95404
Voice: (800) 850-4726; Fax: (707) 544-2363
Web site: www.michaeljfox.org
E-mail: webinfo@parkinsonsaction.org



Parkinson's Disease Foundation

710 W. 168th St., 3rd Fl.
New York, NY 10032
Voice: (800) 457-6676; Fax: (212) 923-4778
Web site: www.pdf.org
E-mail: info@pdf.org



The Parkinson's Institute

1170 Morse Ave.
Sunnyvale, CA 94089
Voice: (800) 786-2958; Fax: (408) 734-9208
Web site: www.parkinsonsinstitute.org
E-mail: outreach@parkinsonsinstitute.org



PEDIATRIC BRAIN TUMOR (See also: Brain Tumor)

Brain Tumor Foundation for Children

1835 Savoy Dr., Suite 316
Atlanta, GA 30341
Voice: (770) 458-5554
Web site: www.btfcgainc.org
E-mail: btfc@bellsouth.net



brain connections

The Childhood Brain Tumor Foundation

20312 Watkins Meadow Dr.
Germantown, MD 20876
Voice: (301) 515-2900
Web site: www.monumental.com/cbtf
E-mail: cbtf@monumental.com



Children's Brain Tumor Foundation

274 Madison Ave., Suite 1301
New York, NY 10016
Voice: (212) 448-9494; Fax: (212) 448-1022
Web site: www.CBTF.org
E-mail: cbtfny@aol.com



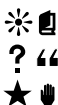
Dana-Farber Cancer Institute

44 Binney St.
Boston, MA 02215
Voice (Pediatric Care): (866) 733-4662
Web site: www.dana-farber.net



Pediatric Brain Tumor Foundation of the United States

315 Ridgefield Ct.
Asheville, NC 28806
Voice: (800) 253-6530; Fax: (828) 665-6894
Web site: www.pbtfus.org
E-mail: pbtfus@pbtfus.org



PITUITARY DISORDERS (See also: Brain Tumor)

Pituitary Tumor Network Association

16350 Ventura Blvd., Suite 231
Encino, CA 91436
Voice: (805) 499-9973; Fax: (805) 499-1523
Web site: www.pituitary.org
E-mail: ptna@pituitary.org



POLIO/POST-POLIO SYNDROME

International Polio Network/Gazette International Networking Institute (GINI)

4207 Lindell Blvd., Suite 110
St. Louis, MO 63108
Voice: (314) 534-0475; TDD: (800) 735-2966, 2466 (V)
Fax: (314) 534-5070
Web site: www.post-polio.org
E-mail: gini_intl@msn.com



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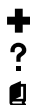
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volunteer opportunities



Post-Polio Syndrome Bibliography

2 Coral Way
Half Moon Bay, CA 94019-2300
Voice: (650) 726-7226
E-mail: PPSBIB@aol.com



POSTPARTUM DEPRESSION

Depression After Delivery

91 E. Somerset St.
Raritan, NJ 08869
Voice: (800) 944-4773; Fax: (908) 541-9712
Web site: www.behavenet.com/dadinc



Postpartum Depression Connection

90 Wheatsheaf Rd.
Ivylnd, PA 18974
Voice: (215) 396-9153; Fax: (215) 396-9554
E-mail: MmLynd@aol.com



POST-TRAUMATIC STRESS DISORDER

National Center for Post-Traumatic Stress Disorder

215 N. Main St.
White River Junction, VT 05009
Voice: (802) 296-5132; Fax: (802) 296-5135
Web site: www.dartncptsd.org
E-mail: ptsd@dartmouth.edu



PRADER-WILLI SYNDROME

Prader-Willi Syndrome Association USA

5700 Midnight Pass Rd., Suite 6
Sarasota, FL 34242
Voice: (800) 926-4797; Fax: (941) 312-0142
Web site: www.pwsausa.org
E-mail: pwsausa@aol.com



PROGRESSIVE SUPRANUCLEAR PALSY

Society for Progressive Supranuclear Palsy

1838 Greene Tree Rd., Suite 515
Baltimore, MD 21208
Voice: (800) 457-4777; Fax: (410) 486-4283
Web site: www.psp.org
E-mail: spsp@erols.com



brain connections

National Institute of Neurological Disorders and Stroke

(See p. 9.)

National Organization for Rare Disorders

(See below.)

PSEUDOTUMOR CEREBRI (See: Rare Disorders)

RARE DISORDERS

National Organization for Rare Disorders

100 Route 37, Fairwood Professional Bldg.

P.O. Box 8923

New Fairfield, CT 06812-8923

Voice: (800) 999-6673; TDD: (203) 746-6927

Fax: (203) 746-6481

Web site: www.rarediseases.org

E-mail: orphan@rarediseases.org



Office of Rare Diseases/National Institutes of Health

31 Center Dr., MSC 2084, Room 1B19

Bethesda, MD 20892-2084

Voice: (301) 402-4336; Fax: (301) 480-9655

Web site: www.rarediseases.info.gov/ord

E-mail: HH70F@nih.gov



REFLEX SYMPATHETIC DYSTROPHY SYNDROME (RSDS)

RSDS Association

116 Haddon Ave., Suite D

Haddonfield, NJ 08033

Voice: (856) 795-8845; Fax: (856) 795-8845

Web site: www.rsdsonline.org

E-mail: jameswbroatch@aol.com



RESTLESS LEGS SYNDROME

RLS Foundation, Inc.

Send self-addressed, stamped envelope to:

RLS Foundation, Inc.

P.O. Box 7050, Dept. WWW

Rochester, MN 55902-2985

Web site: www.rls.org

E-mail: RLSFoundation@rls.org



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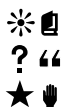
volunteer opportunities



RETT SYNDROME

International Rett Syndrome Association

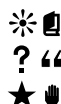
9121 Piscataway Rd., No. 2B
Clinton, MD 20735
Voice: (800) 818-7388; Fax: (301) 856-3336
Web site: www.rettsyndrome.org
E-mail: irsa@rettsyndrome.org



REYE'S SYNDROME

National Reye's Syndrome Foundation

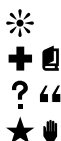
426 N. Lewis, P.O. Box 829
Bryan, OH 43506-0829
Voice: (800) 233-7393; Fax: (419) 636-9897
Web site: www.bright.net/~reyesyn
E-mail: reyessyn@mail.bright.net



SCHIZOPHRENIA

National Alliance for the Mentally Ill (NAMI)

Colonial Place Three
2107 Wilson Blvd., Suite 300
Arlington, VA 22201-3042
Voice: (800) 950-6264; Fax: (703) 524-9094
Web site: www.nami.org



National Alliance for Research on Schizophrenia and Depression (NARSAD)

60 Cutter Mill Rd., Suite 404
Great Neck, NY 11021
Voice: (800) 829-8289; Fax: (516) 487-6930
Web site: www.narsad.org
E-mail: info@narsad.org



SHY-DRAGER SYNDROME

Shy-Drager Syndrome/Multiple Systems Atrophy Support Group

1607 Silver, SE
Albuquerque, NM 87106
Voice: (800) 737-4999



National Institute of Neurological Disorders and Stroke

(See p. 9.)

brain connections

SJOGREN'S SYNDROME

Sjogren's Syndrome Foundation

366 N. Broadway, Suite PH-W2
Jericho, NY 11753
Voice: (800) 475-6473; Fax: (516) 933-6368
Web site: www.sjogrens.org
E-mail: ssf@sjogrens.org



SLEEP DISORDERS (See also: Narcolepsy)

American Sleep Apnea Association

1424 K Street, NW, Suite 302
Washington, DC 20006
Voice: (202) 293-3650; Fax: (202) 293-3656
Web site: www.sleepapnea.org
E-mail: asaa@sleepapnea.org



American Academy of Sleep Medicine

6301 Bandel Rd., #101
Rochester, MN 55901
Voice: (507) 287-6006; Fax: (507) 287-6008
Web site: www.aasmnet.org
E-mail: info@aasmnet.org



National Sleep Foundation

1522 K Street, NW, Suite 500
Washington, DC 20005
Fax: (202) 347-3472
Web site: www.sleepfoundation.org
E-mail: nsf@sleepfoundation.org



SMELL AND TASTE (CHEMOSENSORY) DISORDERS

National Institute on Deafness and Other Communication Disorders (NIDCD)

One Communication Ave.
Bethesda, MD 20892-3456
Voice: (800) 241-1044; TTY: (800) 241-1055
Fax: (301) 907-8830
Web site: www.nih.gov/nidcd
E-mail: nidcd@erie.com



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availability of speakers

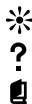
volunteer opportunities



SOTOS SYNDROME

Sotos Syndrome Support Association

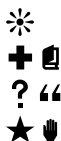
3 Danada Sq., E., 235
Wheaton, IL 60187-8484
Voice: (888) 246-7772
Web site: www.well.com/user/sssas
E-mail: SSSA@well.com



SPASMODIC DYSPHONIA

National Spasmodic Dysphonia Association

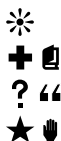
One E. Wacker Dr., Suite 2430
Chicago, IL 60601-1905
Tel: (800) 795-6732; Fax: (312) 803-0138
Web site: www.dystonia-foundation.org/NSDA
E-mail: NSDA@dystonia-foundation.org



SPASMODIC TORTICOLLIS

National Spasmodic Torticollis Association

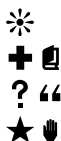
9920 Talbert Ave.
Fountain Valley, CA 92708
Voice: (800) 487-8385; Fax: (714) 378-7830
Web site: www.torticollis.org
E-mail: nstamail@aol.com



SPINA BIFIDA

Spina Bifida Association of America

4590 MacArthur Blvd., NW, Suite 250
Washington, DC 20007-4226
Voice: (800) 621-3141; Fax: (202) 944-3295
Web site: www.sbaa.org
E-mail: sbaa@sbaa.org



SPINAL CORD INJURY (See also: Disability and Rehabilitation; Paralysis)

National Spinal Cord Injury Association

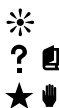
8701 Georgia Ave.
Silver Spring, MD 20910
Voice: (800) 962-9629; Fax: (301) 588-9414
Web site: www.spinalcord.org
E-mail: resource@spinalcord.org



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National Spinal Cord Injury Hotline

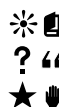
2200 Kernan Dr.
Baltimore, MD 21207
Voice: (800) 526-3456; Fax: (410) 448-6627
Web site: www.scihotline.org
E-mail: scihotline@aol.com



SPINAL MUSCULAR ATROPHY

Families of Spinal Muscular Atrophy

P.O. Box 196
Libertyville, IL 60048
Voice: (800) 886-1762; Fax: (847) 367-7623
Web site: www.fsma.org
E-mail: sma@fsma.org



Shy-Drager Syndrome/Multiple Systems Atrophy Support Group

(See p. 38.)

SPINE-RELATED INJURY/BACK PAIN

North American Spine Society

22 Calendar Ct., 2nd Fl.
La Grange, IL 60525
Voice: (877) 774-6337; Fax: (847) 823-8668
Web site: www.spine.org



STROKE

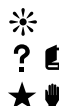
American Stroke Association

(A Division of the American Heart Association)
7272 Greenville Ave.
Dallas, TX 75231
Voice: (800) 553-6321; Fax: (214) 706-5231
Web site: www.strokeassociation.org
E-mail: strokeconnection@heart.org



National Stroke Association

9707 E. Easter Lane
Englewood, CO 80112
Voice: (800) 787-6537; Fax: (303) 649-1328
Web site: www.stroke.org
E-mail: info@stroke.org



National Institute of Neurological Disorders and Stroke

(See p. 9.)

Guide to Symbols

support groups

referrals to doctors

referrals to other information

regional chapters

availability of literature

availability of speakers

volunteer opportunities



STURGE-WEBER DISEASE

The Sturge-Weber Foundation

P.O. Box 418

Mt. Freedom, NJ 07970

Voice: (800) 627-5482; Fax: (973) 895-4846

Web site: www.sturge-weber.com

E-mail: SWF@sturge-weber.com



STUTTERING

National Stuttering Association

5100 E. La Palma, Suite 208

Anaheim Hills, CA 92807

Voice: (800) 364-1677; Fax: (714) 693-7554

Web site: www.nsastutter.org

E-mail: nsastutter@aol.com



Stuttering Foundation of America

3100 Walnut Grove Rd., Suite 603

Memphis, TN 38111

Voice: (800) 992-9392; Fax: (901) 452-3931

Web site: www.stuttersfa.org

E-mail: stutter@vantek.net



SYRINGOMYELIA

American Syringomyelia Alliance Project

P.O. Box 1586, 300 N. Green St., Suite 206

Longview, TX 75606-1586

Voice: (800) 272-7282; Fax: (903) 757-7456

Web site: www.asap4sm.com

E-mail: info@asap4sm.com



TARDIVE DYSKINESIA/TARDIVE DYSTONIA

Tardive Dyskinesia/Tardive Dystonia

National Association

P.O. Box 45732

Seattle, WA 98145-0732

Voice: (206) 522-3166



brain connections

TAY-SACHS DISEASE

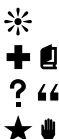
Late Onset Tay-Sachs Foundation

1303 Paper Mill Rd.
Erdenheim, PA 19038
Voice: (800) 672-2022
Web site: www.lotsf.org



National Tay-Sachs and Allied Diseases Association

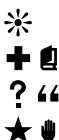
2001 Beacon St., Suite 204
Brighton, MA 02135
Voice: (800) 906-8723; Fax: (617) 277-0134
Web site: www.ntsad.org
E-mail: NTSAD-Boston@worldnet.att.net



TINNITUS

American Tinnitus Association

P.O. Box 5
Portland, OR 97207
Voice: (800) 634-8978; Fax: (503) 248-0024
Web site: www.ata.org
E-mail: tinnitus@ata.org



Better Hearing Institute

(See p. 20.)

National Institute on Deafness and Other Communication Disorders

(See p. 9.)

TOURETTE SYNDROME

Tourette Syndrome Association

42-40 Bell Blvd.
Bayside, NY 11361
Voice: (800) 237-0717; Fax: (718) 279-9596
Web site: <http://tsa.mgh.harvard.edu>
E-mail: tourette@ix.netcom.com



TRIGEMINAL NEURALGIA

Trigeminal Neuralgia Association

P.O. Box 340
Barnegat Light, NJ 08006
Voice: (904) 779-0333; Fax: (609) 361-0982
Web site: www.tna-support.org
E-mail: tna@csionline.net



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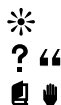
volunteer opportunities



TUBEROUS SCLEROSIS

National Tuberous Sclerosis Association

8181 Professional Pl., Suite 110
Landover, MD 20785
Voice: (800) 225-6872; Fax: (301) 459-0394
Web site: www.nts.org
E-mail: nts@nts.org



VESTIBULAR DISORDERS

Vestibular Disorders Association

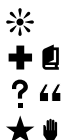
P.O. Box 4467
Portland, OR 97208-4467
Voice: (503) 229-7705; Fax: (503) 229-8064
Web site: www.vestibular.org
E-mail: veda@vestibular.org



VON HIPPEL-LINDAU SYNDROME

Von Hippel-Lindau (VHL) Syndrome Family Alliance

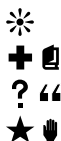
171 Clinton Rd.
Brookline, MA 02146
Voice: (800) 767-4845; Fax: (617) 734-8233
Web site: www.vhl.org
E-mail: info@vhl.org



WILLIAMS SYNDROME

Williams Syndrome Association

1312 N. Campbell, Suite 34
Royal Oak, MI 48067
Voice: (248) 541-3630; Fax: (248) 541-3631
Web site: www.williams-syndrome.org
E-mail: wsooffice@aol.com



WILSON'S DISEASE

Wilson's Disease Association

4 Navaho Dr.
Brookfield, CT 06810
Voice: (800) 399-0266; Fax: (203) 743-6196



Guide to Symbols

- support groups
- referrals to doctors
- referrals to other information

- regional chapters
- availability of literature
- availability of speakers
- volunteer opportunities

For Further Information:

These organizations focus primarily on research, professional support, and/or advocacy. They may, however, be able to provide information or assistance to the public on a limited basis.

Abraham Low Institute

Northfield, IL (847) 441-0445

Acoustical Society of America

Woodbury, NY (516) 576-2360

AIDS National Interfaith Network

Washington, DC (202) 543-1202

American Academy of Addiction Psychiatry

Prairie Village, KS (913) 262-6161

American Academy of Anti-Aging Medicine

Chicago, IL (773) 528-4333

American Academy of Child and Adolescent Psychiatry

Washington, DC (800) 333-7636

American Academy of Pediatrics

Elk Grove Village, IL (847) 228-5005

American Association for Geriatric Psychiatry

Bethesda, MD (301) 654-7850

American College of Medical Genetics

Bethesda, MD (301) 530-7127

American College of Mental Health Administration

Pittsburgh, PA (412) 244-0670

American College of Neuropsychopharmacology

Nashville, TN (615) 322-2075

American Epilepsy Society

Hartford, CT (860) 586-7505

American Federation for Aging Research

New York, NY (212) 752-2327

American Laryngological Association

Boston, MA (617) 355-6417

American Laryngological, Rhinological, and Otological Society

Omaha, NE (402) 498-6666

American Managed Behavioral Healthcare Association

Washington, DC (202) 434-4565

American Methadone Treatment Association

New York, NY (212) 566-5555

American Neurological Association

Minneapolis, MN (612) 545-6284

American Occupational Therapy Association

Bethesda, MD (301) 652-2682

American Society of Neuroradiology

Oak Brook, IL (630) 574-0220

American Spinal Injury Association

Chicago, IL (312) 238-1242

Americans for Medical Progress

Alexandria, VA (800) 426-7872

Association for Repetitive Motion Syndrome

Aurora, CO (303) 369-0803



Children's Brain Disease Foundation

San Francisco, CA (415) 566-5402

Christopher Reeve Paralysis Foundation

Springfield, NJ (800) 225-0292

Coordinated Campaign for Learning Disabilities

Cleveland, OH (888) 478-6463

Foundation for Human Potential

Wilmette, IL (847) 853-9881

Foundation for Spinal Cord Injury Prevention

Detroit, MI (800) 342-0330

The Gerontological Society of America

Washington, DC (202) 842-1275

John Douglas French Alzheimer's Foundation

Los Angeles, CA (800) 477-2243

Judge David L. Bazelon Center for Mental Health Law

Washington, DC (202) 467-5730

Mental Illness Research Association

Bloomfield Hills, MI (800) 896-6472

The National Campaign to End Neurological Disorders

Boston, MA (617) 342-3675

National Center for the Study of Wilson's Disease

New York, NY (212) 397-4286

National Council on Spinal Cord Injury

Boston, MA (617) 342-3675

National Foundation for Brain Research

Washington, DC (202) 466-0577

National Organization on Disability

Washington, DC (202) 293-5960

Pilot International Foundation

Macon, GA (912) 743-7403

The Task Force on Science, Health Care, and the Economy

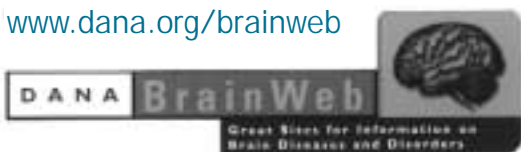
Boston, MA (617) 342-3672

ZERO TO THREE

Washington, DC (202) 638-1144

Get the answers
you need from the
Internet's best
providers of
information on
brain disorders:

www.dana.org/brainweb



The Dana Brain Web Great Sites for Information on Brain Diseases and Disorders

Selected as a "Neuroscience on the Internet 'Best Bet'"
(1997) and a Lycos Top 5% Site (1997)

It can be difficult to find resources helpful for your particular interest when searching for brain-related information on the Internet. The *Dana BrainWeb* can speed you to the precise information you need.

For each of 23 common brain diseases and disorders, the Dana Alliance for Brain Initiatives has selected, reviewed, and validated up to four sites that provide current information for the layperson, including descriptions of the disease, FAQs (Frequently Asked Questions), background for talking with a physician, treatment options, support for families and caregivers, and sources of more information.

Many of these sites also offer extensive links to other Internet sites focused on the same disease or disorder. In addition, the *BrainWeb* provides links to some of the best general neuroscience and health sites. Areas covered include:

- Alcohol and Drug Abuse • Alzheimer's Disease • ALS (Amyotrophic Lateral Sclerosis or Lou Gehrig's Disease) • Anxiety • Autism • Blindness / Vision Impairment • Brain Tumors • Cerebral Palsy • Deafness / Hearing Impairment • Depression / Manic Depression • Epilepsy • Headache • Head Injury • Huntington's Disease • Learning Disabilities • Multiple Sclerosis • Pain (Chronic) • Parkinson's Disease • Schizophrenia • Sleep Disorders • Spinal Cord Injury • Stroke • Tourette Syndrome

New sites are added quarterly to the *BrainWeb*, so check back often.



Publications From the Dana Press

The Dana Press, publisher for the Charles A. Dana Foundation and the Dana Alliance for Brain Initiatives, produces periodicals, reports, and books about the brain for general readers.

Cerebrum: The Dana Forum on Brain Science. Paid subscription quarterly journal of ideas. Articles, debates, and reviews are by the world's top neuroscientists and other thinkers. Request more information by writing to Editor, *Cerebrum*, at the address below.

Request free copies of the following publications from the Dana Press by writing to the address below:

The Brain in the News. Biweekly publication in tabloid format with articles and illustrations on the latest discoveries about the brain, reprinted with permission from major newspapers.

BrainWork: The Neuroscience Newsletter. Bimonthly newsletter with articles for lay readers dealing with the brain, its powers, and its problems.

Delivering Results: An Annual Progress Report on Brain Research. A yearly recap of the progress made in all areas of brain research.

The Dana Classroom Sourcebook for Brain Science. A basic introduction to brain science, geared for high school level and above. Includes classroom activities, a glossary, illustrations of key concepts, Internet resources, an annotated bibliography, and more.

Write or fax your request to:

The Dana Press
The Charles A. Dana Foundation
745 Fifth Ave., Suite 700
New York, NY 10151
FAX: (212) 317-8721
(Or, use the subscription form on the
Dana Web site, listed below.)

The Dana Press publishes books on the brain for lay readers. *The Longevity Strategy: How to Live to 100 Using the Brain-Body Connection* (\$14.95, paper) by David Mahoney and Richard Restak, M.D., and *States of Mind: New Discoveries About How Our Brains Make Us Who We Are* (\$24.95, cloth), edited by Roberta Conlan, are available in bookstores nationwide.

Guidelines for authors interested in submitting book proposals to the Dana Press are on the Dana Internet site, listed below.

Most Dana Press publications, along with current news and information about the programs and activities of the Charles A. Dana Foundation and the Dana Alliance for Brain Initiatives, can be found on the Dana Internet site, www.dana.org.

Ten Ways You Can Support Brain Research

1. Join in the activities of Brain Awareness Week. For news of dates and events in your area, check the Dana Alliance for Brain Initiatives Web site, www.dana.org/brainweek.
2. Let your friends, neighbors, and co-workers know how important you think brain research is to you and your community.
3. Share information with others about important advances in brain research. Don't assume that public officials are up to date in their knowledge. If you think an article or piece of information about the brain is interesting, it is likely they will, too.
4. Donate your time and support to the organizations or advocacy groups of your choice.
5. Support local colleges and universities that have active teaching and research programs in neuroscience.
6. Stay informed on the brain. Read articles and books and watch television newscasts and science programs that discuss new advances in brain research.
7. Write to newspapers and broadcasters to let them know that you follow and appreciate their media coverage on the brain.
8. Volunteer to be a research subject; scientists learn from studies about how normal brains function.
9. Be a brain booster in your local community; share your knowledge with children and adults.
10. Encourage your doctor to keep informed on the latest developments in brain science.

Brain Connections

*Your Source Guide to Information on Brain Diseases and Disorders
Fifth Edition 2000—2002*

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Editor: David Balog

Research: Kathleen Roina, Tara O'Reggio

Inclusion of an agency does not imply endorsement by the Charles A. Dana Foundation or the Dana Alliance for Brain Initiatives. The intent of this guide is to enable individuals anywhere in the country to contact organizations that may be likely to assist them. Many local groups not listed in Brain Connections offer valuable assistance to patients and their families in individual states or cities. Be sure to ask your doctor or consult your local telephone directory. Information on services offered by each organization was provided by the organizations.

Dana Alliance members Murray Goldstein, D.O., M.P.H., and Roger Rosenberg, M.D., assisted in reviewing the editorial content of this edition.

Produced and distributed by The Dana Press.



*Jane Nevins, Editor in Chief
Walter Donway, Director*