

RESOURCE LIST

Alzheimer's (AD)

To learn about support groups, services, research centers, getting involved in studies, and publications about AD, contact the following:

Alzheimer's Disease Education and Referral (ADEAR) Center

P.O. Box 8250
Silver Spring, MD 20907-8250
(800) 438-4380
www.alzheimers.nia.nih.gov

This service of the NIA offers information and publications on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to AD. Staff answer telephone, e-mail, and written requests and make referrals to local and national resources.

Alzheimer's Association

225 North Michigan Avenue, Suite 1700
Chicago, IL 60611-7633
(800) 272-3900
www.alz.org

This nonprofit association supports families and caregivers of patients with AD and funds research. Chapters nationwide provide referrals to local resources and services, and sponsor support groups and educational programs.

American Health Assistance Foundation

22512 Gateway Center Drive
Clarksburg, MD 20871
(800) 437-2423
(301) 948-3244
www.ahaf.org
eberger@ahaf.org

Provides emergency financial assistance to Alzheimer's disease patients and their caregivers.

Eldercare Locator

(800) 677-1116
www.eldercare.gov

This service of the Administration on Aging, funded by the Federal Government, provides information and referrals to respite care and other home and community services offered by State and Area Agencies on Aging.

Family Caregiver Alliance (FCA)

180 Montgomery Street, Suite 1100
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106
www.caregiver.org
info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

FCA's National Center on Caregiving offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, ALS, head injury, Parkinson's and other debilitating brain disorders that strike adults.

RESOURCE LIST

National Academy of Elder Law Attorneys (NAELA)

1604 North Country Club Road
Tucson, AZ 85716
(520) 881-4005
www.naela.com

NAELA publishes consumer information on estate planning and has an online database of Elder Law Attorneys.

Alzheimer's Disease International

www.alz.co.uk/alzheimers

Alzheimer Society of Canada

www.alzheimer.ca

Dementia Advocacy and Support Network

www.dasninternational.org

Asthma

National Library of Medicine

MedlinePlus
8600 Rockville Pike
Bethesda, MD 20894
(888) FIND-NLM (346-3656)
(301) 594-5983
<http://medlineplus.gov>

Allergy & Asthma Network/Mothers of Asthmatics

2751 Prosperity Avenue, Suite 150
Fairfax, VA 22031
(800) 878-4403 or (703) 641-9595
<http://www.aanma.org>

American Academy of Allergy, Asthma, and Immunology

555 East Wells Street, Suite 1100
Milwaukee, WI 53202-3823
(800) 822-2762
<http://www.aaaai.org>

Asthma and Allergy Foundation of America

1233 20th Street, NW, Suite 402
Washington, DC 20036
(800) 7-ASTHMA (727-8462)
<http://aafa.org>

Autoimmunity

Various parts of the NIH provide information on different aspects of autoimmune diseases. Many nonprofit organizations have patient resources, local chapters, and support groups. The patient's doctor is the best resource to give details about their medical condition.

National Institutes of Health

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

1 AMS Circle
Bethesda, MD 20892-3675
(301) 495-4484 or
(877) 22-NIAMS (226-4267)
TTY: (301) 565-2966
Fax: (301) 718-6366
www.niams.nih.gov

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

National Diabetes Information Clearinghouse (NDIC)
1 Information Way
Bethesda, MD 20892-3560
(301) 654-3327 or
(800) 860-8747
ndic@info.niddk.nih.gov
www.niddk.nih.gov

RESOURCE LIST

NIH Clinical Center Patient Recruitment Office

(800) 411-1222
TTY: 866-411-1010
prpl@mail.cc.nih.gov
<http://clinicalstudies.info.nih.gov/>

National Institute of Allergy and Infectious Diseases

Office of Communications
Building 31, Room 7A25 31
Center Drive, MSC 2520
Bethesda, MD 20892-2520
(301) 496-5717
www.niaid.nih.gov/publications
and
www.niaid.nih.gov/clintrials/default.htm
(for clinical trials information)

National Institute of Neurological Disorders and Stroke

Office of Communication and Public Liaison
P.O. Box 5801
Bethesda, MD 20824
(301) 496-5751 or
(800) 352-9424
braininfo@ninds.nih.gov
www.ninds.nih.gov

Office of Rare Diseases

6100 Executive Boulevard
Room 3B01, MSC 7518
Bethesda, MD 20892-7518
(301) 402-4336
<http://rarediseases.info.nih.gov>

Other Resources Sponsored by the U.S. Department of Health and Human Services

Combined Health Information Database

<http://chid.nih.gov>

National Health Information Center

(301) 565-4167 or
(800) 336-4797
Health Finder: www.healthfinder.gov

Other Organizations

American Academy of Dermatology

P.O. Box 4014
Schaumburg, IL 60168-4014
(847) 330-0230 or
(888) 462-DERM (3376)
Fax: (847) 330-0050
www.aad.org

American Liver Foundation

75 Maiden Lane, Suite 603
New York, NY 10038
(800) GO-LIVER (465-4837) or
(800) 4HEP-USA (443-7872)
info@liverfoundation.org
www.liverfoundation.org

American Academy of Orthopaedic Surgeons

P.O. Box 1998
Des Plaines, IL 60017-1998
(800) 824-BONE (2663)
www.aaos.org

Crohn's and Colitis Foundation of America

National Headquarters
386 Park Avenue South, 17th Floor
New York, NY 10016-8804
(800) 932-2423
www.cdfa.org

American College of Rheumatology

1800 Century Place, Suite 250
Atlanta, GA 30345
(404) 633-3777
Fax: (404) 633-1870
acr@rheumatology.org
www.rheumatology.org

Juvenile Diabetes Research Foundation International

120 Wall Street
New York, NY 10005-4001
(212) 785-9500 or
(800) JDF-CURE (533-2873)
Fax: (212) 785-9595
info@jdrf.org
www.jdrf.org

American Behçet's Disease Association

P.O. Box 19952
Amarillo, TX 79114
(800) 7-BEH CET (723-4238)
www.behcets.com

RESOURCE LIST

American Autoimmune Related Diseases Association

22100 Gratiot Avenue
East Detroit, MI 48021
Literature requests: (800) 598-4668
Phone: (586) 776-3900
Fax: (586) 776-3903
aarda@aol.com
www.aarda.org

American Diabetes Association

Attn: National Call Center
1701 North Beauregard Street
Alexandria, VA 22311
Phone: (800) DIABETES (342-2383)
www.diabetes.org

Arthritis Foundation

P.O. Box 7669
Atlanta, GA 30357
(404) 872-7100 or
(800) 568-4045
www.arthritis.org

Guillain-Barré Syndrome Foundation International

P.O. Box 262
Wynnewood, PA 19096
(610) 667-0131
Fax: (610) 667-7036
info@gbsfi.com
www.guillain-barre.com

Lupus Foundation of America, Inc.

2000 L Street, N.W., Suite 710
Washington, DC 20036
(202) 349-1155 or
(800) 558-0121
info@lupus.org
www.lupus.org

Myasthenia Gravis Foundation of America

1821 University Avenue W., Suite S256
St. Paul, MN 55104
(651) 917-6256 or
(800) 541-5454
Fax: (651) 917-1835
mgfa@myasthenia.org
www.myasthenia.org

The Myositis Association

1233 20th Street, N.W., Suite 402
Washington, DC 20036
(202) 887-0088
Fax: (202) 466-8940
tma@myositis.org
www.myositis.org

National Alopecia Areata Foundation

14 Mitchell Boulevard
San Rafael, CA 94903 or
P.O. Box 150760
San Rafael, CA 94915-0760
(415) 472-3780
Fax: (415) 472-5343
info@naaf.org
www.naaf.org

National Adrenal Diseases Foundation

505 Northern Boulevard
Great Neck, NY 11021
(516) 487-4992
nadffmail@aol.com
www.medhelp.org/nadf

National Multiple Sclerosis Society

733 Third Avenue, 6th Floor
New York, NY 10017-3288
(212) 986-3240 or
(800) 344-4867
Fax: (212) 986-7981
info@nmss.org
www.nmss.org

International Pemphigus Foundation

1540 River Park Drive, Suite 208
Sacramento, CA 95815
(916) 922-1298
Fax: (510) 527-8497
pemphigus@pemphigus.org
www.pemphigus.org

National Vitiligo Foundation

700 Olympic Plaza Circle, Suite 404
Tyler, TX 75701
(903) 595-3713
Fax: (903) 593-1545
info@nvfi.org
www.nvfi.org

National Organization for Rare Disorders

P.O. Box 1968
Danbury, CT 06813-1968
(203) 744-0100 or
(800) 999-6673
TDD: 203-797-9590
orphan@rarediseases.org
www.rarediseases.org

RESOURCE LIST

National Psoriasis Foundation

6600 SW 92nd Avenue, Suite 300
Portland, OR 97223-7195
(503) 244-7404 or
(800) 723-9166
Fax: 503-245-0626
getinfo@psoriasis.org
www.psoriasis.org

Scleroderma Foundation

300 Rosewood Drive, Suite 105
Danvers, MA 01923
(978) 463-5843
Info line: (800) 722-HOPE (4673)
Fax: (978) 463-5809
sfinfo@scleroderma.org
www.scleroderma.org

Scleroderma Research Foundation

220 Montgomery Street, Suite 1411
San Francisco, CA 94104
(415) 834-9444 or
(800) 441-CURE (2873)
Fax: (415) 834-9177
info@sclerodermaresearch.org
www.sclerodermaresearch.org

Sjögren's Syndrome Foundation

6707 Democracy Boulevard, Suite 325
Bethesda, MD 20817
(301) 530-4420 or
(800) 475-6473
Fax: (301) 530-4415
www.sjogrens.org

Spondylitis Association of America

P.O. Box 5872
Sherman Oaks, CA 91413
(800) 777-8189
info@spondylitis.org
www.spondylitis.org

S.L.E. Lupus Foundation

330 Seventh Avenue, Suite 1701
New York, NY 10001
(212) 685-4118 or
(800) 74-LUPUS (745-8787)
Fax: (212) 545-1843
lupus@lupusny.org
www.lupusny.org

Thyroid Foundation of America, Inc.

One Longfellow Place, Suite 1518
Boston, MA 02114
(800) 832-8321
Fax: (617) 534-1515
info@allthyroid.org
www.allthyroid.org

Vasculitis Foundation

P.O. Box 28660
Kansas City, MO 64188-8660
(800) 277-9474
Phone/Fax: (816) 436-8211
vf@vasculitisfoundation.org
www.vasculitisfoundation.org

Cerebral Palsy (CP)

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN

P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424
<http://www.ninds.nih.gov>

RESOURCE LIST

Information also is available from the following organizations:

United Cerebral Palsy (UCP)

1660 L Street, NW
Suite 700
Washington, DC 20036
(202) 776-0406 or (800) USA-5UCP (872-5827)
Fax: (202) 776-0414
national@ucp.org
<http://www.ucp.org>

Works to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities, through our commitment to the principles of independence, inclusion and self-determination.

March of Dimes Birth Defects Foundation

1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100 or (888) MODIMES (663-4637)
Fax: (914) 428-8203
askus@marchofdimes.com
<http://www.marchofdimes.com>

Works to improve the health of babies by preventing birth defects and infant mortality through programs of research, community services, education, and advocacy.

Children's Neurobiological Solutions (CNS) Foundation

1726 Franceschi Road
Santa Barbara, CA 93103
(866) CNS-5580 (267-5580) or (805) 965-8838
info@cnsfoundation.org
<http://www.cnsfoundation.org>

National, non-profit organization whose mission is to accelerate the development of brain repair therapies and cures by supporting cutting-edge collaborative research on brain damage due to childhood illness, injury, or any other cause. Provides information and resources for families and health care providers.

Regional Center

There are 21 Regional Centers in California that have the mandate to provide services to all Californians who have one of five diagnoses that had an onset date before the age of 18: mental retardation, cerebral palsy, epilepsy, autism, and a handicap similar to mental retardation that is substantially handicapping and has an onset before the age or 18. Regional Centers provide case management and purchase services.

United Cerebral Palsy (UCP) Research & Educational Foundation

1660 L Street, NW
Suite 700
Washington, DC 20036
(202) 973-7140 or (800) USA-5UCP (872-5827)
Fax: (202) 776-0414
national@ucp.org
<http://www.ucpresearch.org>

Provides grants for research and training on causes and prevention of cerebral palsy and on improving the quality of life of persons with cerebral palsy.

RESOURCE LIST

Pathways Awareness Foundation [For Children With Movement Difficulties]

150 N. Michigan Avenue

Suite 2100

Chicago, IL 60601

(312) 893-6620 or (800) 955-CHILD (2445)

Fax: (312) 893-6621

friends@pathwaysawareness.org

<http://www.pathwaysawareness.org>

National non-profit organization dedicated to raising awareness about the value of early detection, early therapy, and inclusion for infants and children with movement differences.

Easter Seals

230 West Monroe Street

Suite 1800

Chicago, IL 60606-4802

(312) 726-6200 or (800) 221-6827

Fax: (312) 726-1494

info@easterseals.com

<http://www.easterseals.com>

Provides services to help children and adults with disabilities and/or special needs as well as support to their families. Supports the National AgrAbility Project, a program for farmers, ranchers, and farmworkers with disabilities.

Children's Hemiplegia and Stroke Association (CHASA)

4101 West Green Oaks Boulevard, Ste. 305

PMB 149

Arlington, TX 76016

(817) 492-4325

info437@chasa.org

<http://www.hemi-kids.org>

Nonprofit organization that offers support and information to families of children who have hemiplegia due to stroke or other causes. Sponsors a number of programs for families, offers support groups and information about research studies, and sponsors conferences and a childhood stroke awareness campaign.

Chronic Obstructive Pulmonary Disease (COPD)

COPD Learn More, Breathe Better (NHLBI) <http://www.nhlbi.nih.gov/health/public/lung/copd/index.htm>

Chronic Obstructive Pulmonary Disease (COPD) (American Academy of Family Physicians)

<http://familydoctor.org/online/famdocen/home/articles/706.html>

COPD (Chronic Obstructive Pulmonary Disease) *Interactive Tutorial* (Patient Education Institute) - Requires Flash Player Also available in [Spanish](http://www.nlm.nih.gov/medlineplus/tutorials/copd/htm/index.htm) <http://www.nlm.nih.gov/medlineplus/tutorials/copd/htm/index.htm>

Chronic Obstructive Pulmonary Disease Fact Sheet *NIH* (National Heart, Lung, and Blood Institute) - Links to PDF http://www.nhlbi.nih.gov/health/public/lung/other/copd_fact.pdf

American Lung Association

(800) LUNG-USA (586-4872)

<http://www.lungusa.org>

RESOURCE LIST

Cirrhosis

American Liver Foundation (ALF)

75 Maiden Lane, Suite 603
New York, NY 10038-4810
(800) GO-LIVER (465-4837),
(888) 4HEP-USA (443-7872),
or (212) 668-1000
Fax: (212) 483-8179
info@liverfoundation.org
www.liverfoundation.org

Hepatitis Foundation International

504 Blick Drive
Silver Spring, MD 20904-2901
(800) 891-0707 or (301) 622-4200
Fax: (301) 622-4702
hfi@comcast.net
www.hepfi.org

United Network for Organ Sharing

P.O. Box 2484
Richmond, VA 23218
(888) 894-6361 or (804) 782-4800
www.unos.org

Congestive Heart Failure (CHF)

Heart Failure (MedlinePlus) <http://www.nlm.nih.gov/medlineplus/heartfailure.html>

Congestive Heart Failure *Interactive Tutorial* (Patient Education Institute) - Requires Flash Player
<http://www.nlm.nih.gov/medlineplus/tutorials/congestiveheartfailure/htm/index.htm>

Heart Failure *NIH Senior Health* (National Institute on Aging) <http://nihseniorhealth.gov/heartfailure/toc.html>

Heart Failure *NIH* (National Heart, Lung, and Blood Institute)
http://www.nhlbi.nih.gov/health/dci/Diseases/Hf/HF_WhatIs.html

Coronary Artery Bypass Grafting (CABG)

Coronary Artery Disease (Diseases and Conditions Index)
http://www.nhlbi.nih.gov/health/dci/Diseases/Cad/CAD_WhatIs.html

Heart Attack (Diseases and Conditions Index)
http://www.nhlbi.nih.gov/health/dci/Diseases/HeartAttack/HeartAttack_WhatIs.html

NHLBI-Related Public Interest Organizations <http://www.nhlbi.nih.gov/public/grouplist.htm>

Your Guide to Living Well With Heart Disease
http://www.nhlbi.nih.gov/health/public/heart/other/your_guide/living_well.htm

Coronary Artery Bypass Surgery (MedlinePlus)
<http://www.nlm.nih.gov/medlineplus/coronaryarterybypasssurgery.html>

RESOURCE LIST

Diabetes

American Association of Diabetes Educators

100 West Monroe, Suite 400
Chicago, IL 60603-1922
(800) 338-3633
Diabetes Educator Access Line:
(800) TEAMUP4 (832-6874)
Fax: (312) 424-2427
aade@aadenet.org
www.diabeteseducator.org

American Diabetes Association

National Call Center
1701 North Beauregard Street
Alexandria, VA 22311-1742
(800) DIABETES (342-2383)
Fax: (703) 549-6995
askADA@diabetes.org
www.diabetes.org

American Foundation for Urologic Disease

1128 North Charles Street
Baltimore, MD 21201
(800) 242-2383 or (410) 468-1800
admin@afud.org
www.afud.org

American Heart Association

7272 Greenville Avenue
Dallas, TX 75231-4596
(800) AHA-USA1 (242-8721)
Fax: 214-369-3685
www.americanheart.org

American Podiatric Medical Association

9312 Old Georgetown Road
Bethesda, MD 20814-1698
(800) FOOT-CARE (366-8227) or
(301) 571-9200
Fax: 301-530-2752
askapma@apma.org
www.apma.org

Centers for Disease Control and Prevention

National Center for Chronic Disease
Prevention and Health Promotion
Division of Diabetes Translation
Mail Stop K-10
4770 Buford Highway, NE.
Atlanta, GA 30341-3717
(800) CDC-DIAB (232-3422)
Fax: (301) 562-1050
diabetes@cdc.gov
www.cdc.gov/diabetes

Juvenile Diabetes Research Foundation International

120 Wall Street
New York, NY 10005-4001
(800) 533-2873
Fax: (212) 785-9595
info@jdrf.org
www.jdrf.org

Lower Extremity Amputation Prevention Program

HRSA/BPH/DPSP
4350 East-West Highway, 9th floor
Bethesda, MD 20814
(888) 275-4772
www.bphc.hrsa.gov/leap

National Diabetes Education Program

1 Diabetes Way
Bethesda, MD 20892-3600
(800) 438-5383
Fax: (703) 738-4929
www.ndep.nih.gov

National Digestive Diseases Information Clearinghouse

2 Information Way
Bethesda, MD 20892-3570
(800) 891-5389
Fax: (703) 738-4929
nddic@info.niddk.nih.gov
digestive.niddk.nih.gov/about/index.htm

National Heart, Lung, and Blood Institute Health Information Center

P.O. Box 30105
Bethesda, MD 20824-0105
(301) 592-8573
Fax: (301) 592-8563
nhlbiinfo@nhlbi.nih.gov
www.nhlbi.nih.gov

National Institute of Diabetes and Digestive and Kidney Diseases

National Diabetes Information Clearinghouse
1 Information Way
Bethesda, MD 20892
(800) 860-8747
<http://diabetes.niddk.nih.gov/>

RESOURCE LIST

National Institute of Neurological Disorders and Stroke

Brain Resources and Information Network
(BRAIN)
P.O. Box 5801
Bethesda, MD 20824-5801
(800) 352-9424
Fax: (301) 402-2186
www.ninds.nih.gov

National Kidney and Urologic Diseases Information Clearinghouse

3 Information Way
Bethesda, MD 20892-3580
(800) 891-5390
Fax: (703) 738-4929
nkudic@info.niddk.nih.gov
kidney.niddk.nih.gov

Pedorthic Footwear Association

7150 Columbia Gateway Drive, Suite G
Columbia, MD 21046-1151
(800) 673-8447 or
(410) 381-7278
Fax: (410) 381-1167
www.pedorthics.org

Weight-control Information Network

1 WIN Way
Bethesda, MD 20892-3665
(877) 946-4627
Fax: (202) 828-1028
win@info.niddk.nih.gov
www.win.niddk.nih.gov

Diabetes Teachers (nurses, dietitians, pharmacists, and other health professionals) To find a diabetes teacher near, call the American Association of Diabetes Educators toll-free at (800) 832-6874.

Recognized Diabetes Education Programs (teaching programs approved by the American Diabetes Association) To find a program nearby, call (800) DIABETES (342-2383) or look at its Internet home page at www.diabetes.org and click on "Diabetes Info."

Dietitians To find a dietitian nearby, call The American Dietetic Association's National Center for Nutrition and Dietetics at (800) 366-1655 or look at its Internet home page at www.eatright.org and click on "Find a Dietitian."

Fibromyalgia

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

National Institutes of Health
1 AMS Circle
Bethesda, MD 20892-3675
(877) 22-NIAMS (226-4267)
TTY: (301) 565-2966
Fax: (301) 718-6366
NIAMSInfo@mail.nih.gov
www.niams.nih.gov

National Center for Complementary and Alternative Medicine

National Institutes of Health
P.O. Box 7923
Gaithersburg, MD 20898-7923
(888) 644-6226
TTY: (866) 464-3615
Fax: (866) 464-3616
info@nccam.nih.gov
www.nccam.nih.gov

American College of Rheumatology/Association of Rheumatology Health Professionals

1800 Century Place, Suite 250
Atlanta, GA 30345-4300
(404) 633-3777
Fax: (404) 633-1870
www.rheumatology.org

Advocates for Fibromyalgia Funding, Treatment, Education, and Research

P.O. Box 768
Libertyville, IL 60048-0766
(847) 362-7807
Fax: (847) 680-3922
info@affter.org
www.affter.org

RESOURCE LIST

Fibromyalgia Network

P.O. Box 31750
Tucson, AZ 85751-1750
(800) 853-2929
www.fmnetnews.com
National Fibromyalgia Association
2200 North Glassell Street, Suite A
Orange, CA 92865
(714) 921-0150
www.fmaware.org

Arthritis Foundation

1330 West Peachtree Street, Suite 100
Atlanta, GA 30309
(404) 872-7100 or
(800) 568-4045
or call your local chapter
(To find your local chapter, check your phone
directory or visit the foundation's Web site.)
www.arthritis.org

National Fibromyalgia Partnership

P.O. Box 160
Linden, VA 22642-0160
(866) 725-4404
Fax: (866) 666-2727
mail@fmpartnership.org
www.fmpartnership.org

Hypertension (HTN)

High Blood Pressure *NIH* (National Heart, Lung, and Blood Institute)
http://www.nhlbi.nih.gov/health/dci/Diseases/Hbp/HBP_WhatIs.html

High Blood Pressure (MedlinePlus)
<http://www.nlm.nih.gov/medlineplus/highbloodpressure.html>

Your Guide to Lowering High Blood Pressure (interactive Web site)
<http://www.nhlbi.nih.gov/hbp/index.html>

Interactive Tutorial on Hypertension (Patient Education Institute)
<http://www.nlm.nih.gov/medlineplus/tutorials/hypertension/htm/index.htm>

High Blood Pressure: Things You Can Do to Help Lower Yours (American Academy of Family Physicians)
Also available in Spanish
<http://familydoctor.org/online/famdocen/home/common/heartdisease/risk/092.html>

American Heart Association

National Center
7272 Greenville Avenue
Dallas, TX 75231
AHA: (800) AHA-USA-1
or (800) 242-8721

RESOURCE LIST

Joint Replacement

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

1 AMS Circle
Bethesda, MD 20892-3675
(301) 495-4484 or (877) 22-NIAMS (226-4267)
TTY: (301) 565-2966
Fax: (301) 718-6366
NIAMSInfo@mail.nih.gov
www.niams.nih.gov

The NIAMS, a part of the Department of Health and Human Services' National Institutes of Health, leads the Federal Government research effort in arthritis and other diseases that affect the muscles, bones, joints, and skin. The NIAMS supports research and research training throughout the United States, as well as on the NIH campus in Bethesda, Maryland. The NIAMS Office of Communications and Public Liaison provides health and research information for the public through the NIAMS Information Clearinghouse.

Office of Medical Applications of Research (OMAR) National Institutes of Health

Building 31, Room 1B03
31 Center Drive, MSC 2082
Bethesda, MD 20892-2082
(301) 496-5641
<http://odp.od.nih.gov/omar>

OMAR is the focal point for assessing medical practice and state of the science on behalf of the medical community and the public. It works closely with NIH Institutes or Centers to assess, translate, and disseminate the results of biomedical research that can be used in the delivery of health services to the public. Several consensus statements on joint replacement surgery are available on its Web site.

MedlinePlus

www.medlineplus.gov
MedlinePlus is the National Library of Medicine's Web site for consumer health information.

American Academy of Orthopaedic Surgeons (AAOS)

P.O. Box 2058
Des Plaines, IL 60017
(800) 824-BONE (2663)
www.aaos.org

The academy provides education and practice management services for orthopaedic surgeons and allied health professionals. It also serves as an advocate for improved patient care and informs the public about the science of orthopaedics. The orthopaedist's scope of practice includes disorders of the body's bones, joints, ligaments, muscles, and tendons. For a single copy of an AAOS brochure, send a self-addressed stamped envelope to the address above or visit the AAOS Web site.

American College of Rheumatology

1800 Century Place, Suite 250
Atlanta, GA 30345
(404) 633-3777
Fax: (404) 633-1870
www.rheumatology.org

This association provides referrals to doctors and other health professionals who treat arthritis and other rheumatic diseases that may lead to joint replacement surgery. The association also provides educational materials and guidelines.

RESOURCE LIST

Arthritis Foundation

1330 West Peachtree Street, Suite 100

Atlanta, GA 30309

(404) 872-7100 or

(800) 568-4045

or your local chapter listed in the telephone book

www.arthritis.org

The Arthritis Foundation is the major voluntary organization devoted to supporting research into arthritis and other rheumatic diseases and providing education and other services to people with rheumatic diseases. This foundation publishes free pamphlets, and local chapters provide many services in the community, such as exercise classes, self-help courses, and support groups.

Kidney Failure

American Association of Kidney Patients

3505 East Frontage Road, Suite 315

Tampa, FL 33607

(800) 749-2257 or

(813) 636-8100

Fax: (813) 636-8122

info@aakp.org

www.aakp.org

American Kidney Fund

6110 Executive Boulevard, Suite 1010

Rockville, MD 20852

(800) 638-8299 or

(301) 881-3052

Fax: (301) 881-0898

helpline@akfinc.org

www.akfinc.org

Life Options/Rehabilitation Resource Center

c/o Medical Education Institute, Inc.

414 D'Onofrio Drive, Suite 200

Madison, WI 53719

(800) 468-7777

Fax: (608) 833-8366

lifoptions@MEIresearch.org

www.lifeoptions.org

www.kidneyschool.org

National Hospice and Palliative Care Organization

1700 Diagonal Road, Suite 625

Alexandria, VA 22314

(800) 658-8898

caringinfo@nhpco.org

www.caringinfo.org

www.nhpco.org

National Kidney Foundation

30 East 33rd Street

New York, NY 10016

(800) 622-9010 or

(212) 889-2210

info@kidney.org

www.kidney.org

Polycystic Kidney Disease Foundation

9221 Ward Parkway, Suite 400

Kansas City, MO 64114-3367

(800) PKD-CURE (753-2873) or

(816) 931-2600

Fax: (816) 931-8655

pkdcure@pkdcure.org

www.pkdcure.org

United Network for Organ Sharing

P.O. Box 2484

Richmond, VA 23218

(888) 894-6361

www.unos.org

RESOURCE LIST

Additional Reading

If you would like to learn more about kidney failure and its treatment, you may be interested in reading

AAKP Patient Plan

This is a series of booklets and newsletters that cover the different phases of learning about kidney failure, choosing a treatment, and adjusting to changes.

American Association of Kidney Patients

3505 East Frontage Road, Suite 315

Tampa, FL 33607

(800) 749-2257

info@aakp.org

www.aakp.org

Medicare Coverage of Kidney Dialysis and Kidney Transplant Services

Publication Number CMS-10128

U.S. Department of Health and Human Services

Centers for Medicare & Medicaid Services

7500 Security Boulevard

Baltimore, MD 21244-1850

(800) MEDICARE (633-4227)

TDD: (877) 486-2048

www.medicare.gov/publications/pubs/pdf/esrdcoverage.pdf

National Kidney Foundation (NKF) Patient Education Brochures

(includes materials based on NKF's Dialysis Outcomes Quality Initiative)

National Kidney Foundation, Inc.

30 East 33rd Street, Suite 1100

New York, NY 10016

(800) 622-9010 or

(212) 889-2210

www.kidney.org

Newsletters and Magazines

Family Focus Newsletter

(published quarterly)

National Kidney Foundation, Inc.

30 East 33rd Street, Suite 1100

New York, NY 10016

(800) 622-9010 or (212) 889-2210

www.kidney.org

For Patients Only *(published six times a year)*

ATTN: Subscription Department

18 East 41st Street, 20th Floor

New York, NY 10017-6222

Renalife *(published quarterly)*

American Association of Kidney Patients

3505 East Frontage Road, Suite 315

Tampa, FL 33607

(800) 749-2257

Email: info@aakp.org

www.aakp.org

RESOURCE LIST

Books

Bowes and Church's Food Values of Portions Commonly Used

Eighteenth Edition
Jean A.T. Pennington and Judith S. Douglass
J.P. Lippincott Co. 2004
ISBN: 0-7817-4429-6

The Complete Book of Food Counts

Seventh Edition
Corinne T. Netzer
Dell Publishing Co. 2005
ISBN: 0-440-24123-5

Brochures

Nutrition and Hemodialysis

National Kidney Foundation
30 East 33rd Street
New York, NY 10016
(800) 622-9010 or (212) 889-2210

How to Increase Calories in Your Renal Diet

National Kidney Foundation
30 East 33rd Street
New York, NY 10016
(800) 622-9010 or (212) 889-2210

Cookbooks

These cookbooks provide recipes for people on dialysis:

The Renal Gourmet

Mardy Peters
ISBN: 0-9641730-0-X
Emenar Incorporated
13n625 Coombs Road
Elgin, IL 60123
Fax: (847) 741-8696
webmaster@kidney-cookbook.com
www.kidney-cookbook.com

Creative Cooking for Renal Diabetic Diets

Cleveland Clinic Foundation
ISBN: 0-941511-01-4
Senay Publishing
P.O. Box 397
Chesterland, OH 44026
(866) 648-2693
jsenay@adelphia.net
www.patientsupport.net/patsupport/renal-diet-cookbooks.htm

Southwest Cookbook for People on Dialysis

Developed by the El Paso Chapter Council on Renal Nutrition and the National Kidney Foundation of Texas, Inc. Published by a grant from Amgen Inc.
www.epogen.com/patient/pdf/southwest_cookbook.pdf

Kidney Friendly Comfort Foods

Shire US Inc.
Wayne, PA 19087
(866) 896-6152
www.fosrenol.com/Consumers/Resources/CookBooks.aspx

Creative Cooking for Renal Diets

Cleveland Clinic Foundation
ISBN: 0-941511-00-6
Senay Publishing
P.O. Box 397
Chesterland, OH 44026
(866) 648-2693
jsenay@adelphia.net
www.patientsupport.net/patsupport/renal-diet-cookbooks.htm

Cooking for David

Culinary Kidney Cooks
P.O. Box 468
Huntington Beach, CA 92648
(714) 842-4684
Eric.Brooks@CulinaryKidneyCooks.com
www.culinarykidneycooks.com

More Online Information

The American Association of Kidney Patients provides an online nutrition counter at www.aakp.org/brochures/nutrition-counter.

The National Kidney Foundation offers many fact sheets for patients with kidney disease at www.kidney.org on the Internet.

RESOURCE LIST

About the Kidney Failure Series

The publications of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Kidney Failure Series can help learn about the specific issues you will face.

Booklets

- Eat Right to Feel Right on Hemodialysis
<http://kidney.niddk.nih.gov/kudiseases/pubs/eatright/>
- Kidney Failure: Choosing a Treatment That's Right for You
<http://kidney.niddk.nih.gov/kudiseases/pubs/choosingtreatment/index.htm>
- Kidney Failure Glossary
<http://kidney.niddk.nih.gov/kudiseases/pubs/glossary/index.htm>
- Treatment Methods for Kidney Failure: Hemodialysis
<http://kidney.niddk.nih.gov/kudiseases/pubs/hemodialysis/index.htm>
- Treatment Methods for Kidney Failure: Peritoneal Dialysis
<http://kidney.niddk.nih.gov/kudiseases/pubs/peritoneal/index.htm>
- Treatment Methods for Kidney Failure: Transplantation
<http://kidney.niddk.nih.gov/kudiseases/pubs/transplant/index.htm>

Fact Sheets

- Amyloidosis and Kidney Disease
<http://kidney.niddk.nih.gov/kudiseases/pubs/amyloidosis/>
- Anemia in Kidney Disease and Dialysis
<http://kidney.niddk.nih.gov/kudiseases/pubs/anemia/>
- Financial Help for Treatment of Kidney Failure
<http://kidney.niddk.nih.gov/kudiseases/pubs/financialhelp/>
- Hemodialysis Dose and Adequacy
<http://kidney.niddk.nih.gov/kudiseases/pubs/hemodialysisdose/>
- Kidney Failure: What to Expect
<http://kidney.niddk.nih.gov/kudiseases/pubs/expect/>
- Peritoneal Dialysis Dose and Adequacy
<http://kidney.niddk.nih.gov/kudiseases/pubs/peritonealdose/>
- Renal Osteodystrophy
<http://kidney.niddk.nih.gov/kudiseases/pubs/renalosteodystrophy/>
- Vascular Access for Hemodialysis
<http://kidney.niddk.nih.gov/kudiseases/pubs/vascularaccess/>

Systemic Lupus Erythematosus (Lupus)

National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse NIAMS/National Institutes of Health

1 AMS Circle
Bethesda, MD 20892-3675
(301) 495-4484 or (877) 22-NIAMS (226-4267)
TTY: (301) 565-2966
Fax: (301) 718-6366
NIAMSInfo@mail.nih.gov
www.niams.nih.gov/

The National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse is a public service sponsored by the NIAMS that provides health information and information sources. The clearinghouse provides information on lupus. Fact sheets, additional information, and research updates can also be found on the NIAMS Web site at www.niams.nih.gov.

RESOURCE LIST

Clinicaltrials.gov

The Department of Health and Human Services' National Institutes of Health, through its National Library of Medicine, has developed ClinicalTrials.gov to provide patients, family members, and members of the public current information about clinical research studies. You can search for trials by disease, location, treatment, or by funding organization at the Web site clinicaltrials.gov.

American College of Rheumatology (ACR) Association of Rheumatology Health Professionals

1800 Century Place, Suite 250

Atlanta, GA 30345

(404) 633-3777

Fax: (404) 633-1870

www.rheumatology.org

The American College of Rheumatology (ACR) is an organization of doctors and associated health professionals who specialize in arthritis and related diseases of the bones, joints, and muscles. The Association of Rheumatology Health Professionals, a division of ACR, aims to enhance the knowledge and skills of rheumatology health professionals and to promote their involvement in rheumatology research, education, and quality patient care. The association also works to advance and promote basic and continuing education in rheumatology for health professionals who provide care to people with rheumatic diseases.

Alliance for Lupus Research, Inc. (ALR)

28 West 44th Street, Suite 1217

New York, NY 10036

(212) 218-2840 or (800) 867-1743

www.lupusresearch.org

The Alliance for Lupus Research, Inc. (ALR), is a nonprofit organization devoted exclusively to the support of promising research for the prevention, treatment, and cure of lupus. Through accelerated, focused, goal-oriented research programs, the ALR aims to promote basic and clinical sciences to achieve major advances leading to a better understanding of the causes of lupus.

American Autoimmune Related Diseases Association (AARDA)

22100 Gratiot Avenue

East Detroit, MI 48021

(586) 776-3900 or (800) 598-4668

aarda@aarda.org

www.aarda.org

The American Autoimmune Related Diseases Association (AARDA) is the only national nonprofit voluntary health agency dedicated to bringing a national focus and collaborative effort to the over 100 known autoimmune diseases through education, awareness, research, and patient services. By collaborating with the National Coalition of Autoimmune Patient Groups (NCAPG), AARDA supports legislative advocacy for autoimmune disease patients. AARDA provides free patient education information, physician and agency referrals, forums and symposia, and a quarterly newsletter.

Arthritis Foundation

P.O. Box 7669

Atlanta, GA 30357-0669

(404) 872-7100 or (800) 568-4045 or your local chapter (listed in the telephone directory)

www.arthritis.org

The Arthritis Foundation is the major voluntary organization devoted to supporting arthritis research and providing educational and other services to individuals with arthritis. It publishes free pamphlets and a magazine for members on all types of arthritis. It also provides up-to-date information on research and treatment, nutrition, alternative therapies, and self-management strategies for patients with lupus and other autoimmune diseases. Chapters nationwide offer exercise programs, classes, support groups, physician referral services, and free literature. For more information, call your local chapter, listed in the white pages of the phone book, or contact the Arthritis Foundation at the above address.

RESOURCE LIST

Lupus Clinical Trials Consortium, Inc. (LCTC)

47 Hulfish Street, Suite 442
Princeton, NJ 08540
(609) 921-6670

The LCTC is a nonprofit organization that encourages the identification and testing of promising new therapies for lupus. It provides infrastructure support grants to certain academic institutions to support their clinical research activities; encourages lupus clinical researchers from those institutions to share their expertise; supports and conducts educational efforts to show the need for lupus clinical research; and disseminates scientific insights to advance the discovery of new lupus therapies.

Lupus Foundation of America (LFA), Inc.

2000 L Street, N.W., Suite 710
Washington, DC 20036
(202) 349-1155 or (800) 558-0121
www.lupus.org

The LFA assists local chapters in providing services to people with lupus, works to educate the public about lupus, and supports lupus research. Through a network of more than 500 branches and support groups, the chapters provide education through information and referral services, health fairs, newsletters, publications, and seminars. Chapters provide support to people with lupus, their families, and friends through support group meetings, hospital visits, and telephone help lines.

Rheuminations, Inc.

221 East 48th Street, Ground Floor
New York, NY 10017
(212) 593-5180
Fax: (212) 593-5181
www.dxlupus.org

Rheuminations, Inc. is a private, nonprofit foundation committed to funding excellence in medical research to achieve a better understanding of the causes of lupus and to bring new treatments to market; to educate and to empower those who live with lupus and those who care for them; to establish a higher level of public awareness about the disease.

SLE Foundation, Inc.

330 Seventh Avenue, Suite 1701
New York, NY 10001
(212) 685-4118 or (800) 74-LUPUS (745-8787)
www.lupusny.org

The foundation supports and encourages medical research to find the cause and cure of lupus and improve its diagnosis and treatment. It also provides a wide variety of services to help patients with lupus and their families. In addition, this voluntary organization conducts a broad-based public education program to raise awareness of lupus and increase understanding of this serious, chronic, autoimmune disease.

Multiple Sclerosis (MS)

National Institute of Neurological Disorders and Stroke, Brain Resources and Information Network

BRAIN

P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424
<http://www.ninds.nih.gov>

RESOURCE LIST

Information also is available from the following organizations:

Clearinghouse on Disability Information

Special Education & Rehabilitative Services Communications & Customer Service Team
550 12th Street, SW, Rm. 5133
Washington, DC 20202-2550
(202) 245-7307 (202) 205-5637 (TTD)
Fax: (292) 245-7636
<http://www.ed.gov/about/offices/list/osers>

Multiple Sclerosis Association of America

706 Haddonfield Road
Cherry Hill, NJ 08002
(856) 488-4500 or (800) 532-7667
Fax: (856) 661-9797
msaa@msaa.com abednar@msassociation.org
www.msassociation.org

National, non-profit organization dedicated to enhancing the quality of life for those affected by multiple sclerosis. Provides ongoing support and direct services to individuals with MS and their families and works to promote a greater understanding of the needs and challenges of those who face physical obstacles.

International Essential Tremor Foundation

P.O. Box 14005
Lenexa, KS 66285-4005
(913) 341-3880 or (888) 387-3667
Fax: (913) 341-1296
staff@essentialtremor.org
<http://www.essentialtremor.org>

Provides educational information, funds research in tremor disorders, and offers services and support to individuals diagnosed with essential tremor, their families, and health care providers. Information and support includes a quarterly newsletter, support groups, and physician information and referrals.

Multiple Sclerosis Foundation

6350 North Andrews Avenue
Ft. Lauderdale, FL 33309-2130
(954) 776-6805 or (888) MSFOCUS (673-6287)
Fax: (954) 351-0630
support@msfocus.org
<http://www.msfocus.org>

Dedicated to helping people with MS, the Multiple Sclerosis Foundation offers a wide array of free services including: national toll-free support, educational programs, homecare services, support groups, assistive technology programs, publications, a comprehensive website, and more programs to improve the quality of life for those affected by MS.

National Rehabilitation Information Center (NARIC)

4200 Forbes Boulevard
Suite 202
Lanham, MD 20706-4829
(301) 459-5900 or (301) 459-5984 (TTY) (800) 346-2742
Fax: (301) 562-2401
naricinfo@heitechservices.com
<http://www.naric.com>

RESOURCE LIST

National Multiple Sclerosis Society

733 Third Avenue
6th Floor
New York, NY 10017-3288
(212) 986-3240 or (800) 344-4867 (FIGHTMS)
Fax: (212) 986-7981
nat@nmss.org
<http://www.nationalmssociety.org>

Funds research, helps families stay together, provides accurate and up-to-date information, helps with employment issues, offers free counseling, runs self-help groups, advocates for people with disabilities, and provides referrals to medical professionals.

National Ataxia Foundation (NAF)

2600 Fernbrook Lane North
Suite 119
Minneapolis, MN 55447-4752
763) 553-0020
Fax: (763) 553-0167
naf@ataxia.org
<http://www.ataxia.org>

(Encourages and supports research into the hereditary ataxias, a group of chronic and progressive neurological disorders affecting coordination. Sponsors chapters and support groups throughout the U.S.A. and Canada. Publishes a quarterly newsletter and educational literature on the various forms of ataxia.

National Organization for Rare Disorders (NORD)

P.O. Box 1968
(55 Kenosia Avenue)
Danbury, CT 06813-1968
(203) 744-0100 Voice Mail (800) 999-NORD (6673)
Fax: (203) 798-2291
orphan@rarediseases.org
<http://www.rarediseases.org>

Federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. Committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

Accelerated Cure Project for Multiple Sclerosis

300 Fifth Avenue
Waltham, MA 02451
(781) 487-0008
Fax: (781) 487-0009
info@acceleratedcure.org
<http://www.acceleratedcure.org>

National nonprofit organization dedicated to the creation and execution of a plan to cure MS by determining its causes. Developing a multi-disciplinary blood, tissue, and data bank.

American Autoimmune Related Diseases Association

22100 Gratiot Avenue
Eastpointe
East Detroit, MI 48201-2227
(586) 776-3900 or (800) 598-4668
Fax: (586) 776-3903
aarda@aarda.org
<http://www.aarda.org>

National organization that works to alleviate suffering and the socioeconomic impact of autoimmunity. Dedicated to the eradication of autoimmune diseases through fostering and facilitating collaboration in the areas of education, research, and patient services.

RESOURCE LIST

Osteoarthritis

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

National Institutes of Health

1 AMS Circle

Bethesda, MD 20892-3675

(301) 495-4484 or

(877) 22-NIAMS (226-4267)

TTY: (301) 565-2966

Fax: (301) 718-6366

NIAMSInfo@mail.nih.gov

www.niams.nih.gov

NIAMS provides information about various forms of arthritis and other rheumatic diseases, and other bone, muscle, joint, and skin diseases. It distributes patient and professional education materials and refers people to other sources of information. Additional information and updates can also be found on the NIAMS Web site.

NIH Osteoporosis and Related Bone Diseases~National Resource Center

2 AMS Circle

Bethesda, MD 20892-3676

(202) 223-0344 or (800) 624-BONE

TTY: (202) 466-4315

Fax: (202) 293-2356

www.niams.nih.gov/bone

The NIH Osteoporosis and Related Bone Diseases~National Resource Center provides patients, health professionals, and the public with an important link to resources and information on metabolic bone diseases. The mission of NIH ORBD~NRC is to expand awareness and enhance knowledge and understanding of the prevention, early detection, and treatment of these diseases as well as strategies for coping with them. The center provides information on osteoporosis, Paget's disease of bone, osteogenesis imperfecta, primary hyperparathyroidism, and other metabolic bone diseases and disorders.

American Academy of Orthopaedic Surgeons (AAOS)

P.O. Box 1998

Des Plaines, IL 60017

(847) 823-7186 or

(800) 824-BONE (2663)

Fax: (847) 823-8125

www.aaos.org

The academy provides education and practice management services for orthopaedic surgeons and allied health professionals. It also serves as an advocate for improved patient care and informs the public about the science of orthopaedics. The orthopaedist's scope of practice includes disorders of the body's bones, joints, ligaments, muscles, and tendons. For a single copy of an AAOS brochure, send a self-addressed stamped envelope to the address above or visit the AAOS Web site.

American College of Rheumatology

1800 Century Place, Suite 250

Atlanta, GA 30345

(404) 633-3777

Fax: (404) 633-1870

www.rheumatology.org

This association provides referrals to doctors and health professionals who work on arthritis, rheumatic diseases, and related conditions. It also provides educational materials and guidelines for the treatment of osteoarthritis.

RESOURCE LIST

American Physical Therapy Association

1111 North Fairfax Street
Alexandria, VA 22314-1488
(703) 684-2782 or
(800) 999-APTA (2782)
Fax: (703) 684-7343
www.apta.org

This association is a national professional organization representing physical therapists, allied personnel, and students. Its objectives are to improve research, public understanding, and education in the physical therapies.

Arthritis Foundation

P.O. Box 7669
Atlanta, GA 30357-0669
(404) 872-7100 or
(800) 568-4045 or your local chapter
(listed in the telephone directory)
www.arthritis.org

This is the major voluntary organization devoted to arthritis. The foundation publishes free informational brochures on various types of arthritis, including osteoarthritis, as well as a monthly magazine for members that provides up-to-date information on all forms of arthritis. The foundation also can provide addresses and phone numbers for local chapters and physician and clinic referrals.

Osteoporosis

NIH Osteoporosis and Related Bone Diseases~National Resource Center (NIH ORBD~NRC)

2 AMS Circle
Bethesda, MD 20892-3676
(202) 223-0344 or (800) 624-BONE (2663)
TTY: (202) 466-4315
Fax: (202) 293-2356
NIAMSBoneInfo@mail.nih.gov
www.niams.nih.gov/bone

The NIH Osteoporosis and Related Bone Diseases~National Resource Center (ORBD~NRC) provides patients, health professionals, and the public with an important link to resources and information on osteoporosis and other metabolic bone diseases. The mission of NIH ORBD~NRC is to expand awareness and enhance knowledge and understanding of the prevention, early detection, and treatment of these diseases as well as strategies for coping with them. The center has a wide range of publications on osteoporosis, including "Bone Health and Osteoporosis: A Report of the Surgeon General" and an accompanying booklet written for the general public. Fact sheets on osteoporosis include more detailed information on topics such as prevention of falls and fractures, calcium supplements, exercise, quality-of-life issues, and osteoporosis in men and various ethnic groups. Fact sheets on bone health and osteoporosis are also available in Spanish and Chinese. These and other fact sheets are available by mail and on the center's Web site, which also provides links to other sources of information on osteoporosis.

RESOURCE LIST

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

National Institutes of Health
1 AMS Circle
Bethesda, MD 20892-3675
(301) 495-4484 or (877) 22-NIAMS (226-4267)
TTY: (301) 565-2966
Fax: (301) 718-6366
NIAMInfo@mail.nih.gov
www.niams.nih.gov

The NIAMS leads the Federal research effort on osteoporosis and related bone diseases. NIAMS distributes patient and professional educational materials about osteoporosis and can refer people to other sources of information. Through its Web site, NIAMS also provides information about current research related to osteoporosis, as well as health information about the disease. "Kids and Their Bones," a publication produced jointly by NIAMS and the NIH Osteoporosis and Related Bone Diseases~National Resource Center, is available on the NIAMS Web site and by mail.

National Institute on Aging (NIA) Information Center

P.O. Box 8057
Gaithersburg, MD 20898-8057
(800) 222-2225
TTY: (800) 222-4225
www.nia.nih.gov

The National Institute on Aging (NIA), a part of the National Institutes of Health, has a book and video about exercise for older people. For more information and a free publications list, write or call the NIA Information Center. In consultation with NIAMS, NIA has also provided information about the prevention and treatment of osteoporosis on the NIH Senior Health Web site (www.nihseniorhealth.gov), a joint effort of NIA and the National Library of Medicine (NLM).

American Academy of Orthopaedic Surgeons (AAOS)

P.O. Box 2058
Des Plaines, IL 60017
(800) 824-BONE (2663)
www.aaos.org

The academy provides education and practice management services for orthopaedic surgeons and allied health professionals. It also serves as an advocate for improved patient care and informs the public about the science of orthopaedics. The orthopaedist's scope of practice includes disorders of the body's bones, joints, ligaments, muscles, and tendons. For a single copy of an AAOS brochure, send a self-addressed stamped envelope to the address above or visit the AAOS Web site.

American Geriatrics Society (AGS)

The Empire State Building
350 Fifth Avenue, Suite 801
New York, NY 10118
(212) 308-1414
Fax: (212) 832-8646
info@americangeriatrics.org
www.americangeriatrics.org

The American Geriatrics Society (AGS), a national nonprofit organization, is the premier professional organization of health care providers dedicated to improving the health and well-being of all older adults. Through its Web site, it provides information to geriatrics health care professionals, the public, and other concerned individuals dedicated to improving the health, independence, and quality of life of all older people. The AGS provides educational materials on fall prevention, osteoporosis, and bone health for patients and health professionals on its Web site.

RESOURCE LIST

American Society for Bone and Mineral Research (ASBMR)

2025 M Street, NW, Suite 800
Washington, DC 20036-3309, USA
(202) 367-1161
Fax: (202) 367-2161
asbmr@asbmr.org
www.asbmr.org

The American Society for Bone and Mineral Research (ASBMR) is a professional scientific and medical society established to bring together clinical and experimental scientists involved in the study of bone and mineral metabolism. ASBMR encourages and promotes the study of this expanding field through annual scientific meetings; an official journal, the Primer on the Metabolic Bone Diseases and Disorders of Mineral Metabolism; and advocacy and interaction with government agencies and related societies.

National Osteoporosis Foundation (NOF)

1232 22nd Street, NW
Washington, DC 20037-1292
(202) 223-2226
Fax: (202) 223-2237
www.nof.org

The National Osteoporosis Foundation (NOF) is the leading nonprofit, voluntary health organization dedicated to promoting lifelong bone health in order to reduce the widespread prevalence of osteoporosis and associated fractures, while working to find a cure for the disease through programs of research, education, and advocacy. NOF provides information and resources on osteoporosis for patients and the public. It also provides resources and professional relations and education programs on the disease for health professionals.

Food and Drug Administration

(888) 463-6332
<http://www.fda.gov>

Pain

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN

P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424
<http://www.ninds.nih.gov>

Information also is available from the following organizations:

National Institute of Dental and Craniofacial Research (NIDCR)

National Institutes of Health, DHHS
31 Center Drive, Room 5B-55
Bethesda, MD 20892
(301) 496-4261
nidcrinfo@mail.nih.gov
<http://www.nidcr.nih.gov>

RESOURCE LIST

American Chronic Pain Association (ACPA)

P.O. Box 850
Rocklin, CA 95677-0850
(916) 632-0922 or (800) 533-3231
Fax: (916) 632-3208
ACPA@pacbell.net
<http://www.theacpa.org>

Provides self-help coping skills and peer support to people with chronic pain. Sponsors local support groups throughout the U.S. and provides assistance in starting and maintaining support groups.

American Council for Headache Education

19 Mantua Road
Mt. Royal, NJ 08061
(856) 423-0258 or (800) 255-ACHE (2243)
Fax: (856) 423-0082
achehq@talley.com
<http://www.achenet.org>

Non-profit patient-health professional partnership dedicated to advancing the treatment and management of headache and to raising public awareness of headache as a valid, biologically-based illness.

National Headache Foundation

820 N. Orleans
Suite 217
Chicago, IL 60610-3132
(312) 274-2650 or (888) NHF-5552 (643-5552)
Fax: (312) 640-9049
info@headaches.org
<http://www.headaches.org>

Non-profit organization dedicated to service headache sufferers, their families, and the healthcare practitioners who treat them. Promotes research into headache causes and treatments and educates the public.

National Foundation for the Treatment of Pain

P.O. Box 70045
Houston, TX 77270
(713) 862-9332
Fax: (713) 862-9346
NFTPain@cwo.com
<http://www.paincare.org>

Not-for-profit organization dedicated to providing support for patients who are suffering from intractable pain, their families, friends and the physicians who treat them. Offers a patient forum, advocacy programs, information, support resources, and direct medical intervention.

Mayday Fund [For Pain Research]

c/o SPG
136 West 21st Street, 6th Floor
New York, NY 10011
(212) 366-6970
Fax: (212) 366-6979
mayday@maydayfund.org
<http://www.painandhealth.org>

The Mayday Pain Project works to increase awareness and to provide objective information concerning the treatment of pain.

RESOURCE LIST

American Pain Foundation

201 North Charles Street
Suite 710
Baltimore, MD 21201-4111
(888) 615-PAIN (7246)
Fax: (410) 385-1832
info@painfoundation.org
<http://www.painfoundation.org>

Independent non-profit information, education, and advocacy organization serving people with pain. Works to improve the quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating the removal of barriers and increased access to effective pain management.

Arthritis Foundation

1330 West Peachtree Street
Suite 100
Atlanta, GA 30309
(800) 568-4045 or
(404) 872-7100 or (404) 965-7888
Fax: (404) 872-0457
help@arthritis.org
<http://www.arthritis.org>

Volunteer-driven organization that works to improve lives through leadership in the prevention, control, and cure of arthritis and related diseases. Offers free brochures on various types of arthritis, treatment options, and management of daily activities when affected.

Parkinson's Disease (PD)

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN

P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424
<http://www.ninds.nih.gov>

Information also is available from the following organizations:

American Parkinson Disease Association

135 Parkinson Avenue
Staten Island, NY 10305-1425
(718) 981-8001 or (800) 223-2732 Calif: (800) 908-2732
Fax: (718) 981-4399
apda@apdaparkinson.org
<http://www.apdaparkinson.org>

Dedicated to funding Parkinson's disease research. Offers comprehensive medical information and extensive public/professional education and support services.

RESOURCE LIST

Parkinson Alliance

P.O. Box 308
Kingston, NJ 08528-0308
(609) 688-0870 or (800) 579-8440
Fax: (609) 688-0875
admin@parkinsonalliance.org
<http://www.parkinsonalliance.org>

Raises and distributes money for the most promising research leading to a cure for Parkinson's disease. Partners with the Tuchman Foundation to ensure that every dollar donated by individuals and all net proceeds of events go directly to research. The Alliance is also devoted to improving quality of life within the DBS-STN community through an affiliated resource, www.DBS-STN.org.

National Parkinson Foundation

1501 N.W. 9th Avenue
Bob Hope Road
Miami, FL 33136-1494
(305) 243-6666 or (800) 327-4545
Fax: (305) 243-5595
contact@parkinson.org
<http://www.parkinson.org>

Provides research, patient services, clinical studies, public and professional education, and physician referrals at over 60 locations and through a nationwide network of chapters and support groups

Michael J. Fox Foundation for Parkinson's Research

Grand Central Station
P.O. Box 4777
New York, NY 10163
(212) 509-0995
<http://www.michaeljfox.org>

Dedicated to advancing a cure for Parkinson's disease by identifying promising research and raising funds for research support.

Parkinson's Action Network (PAN)

1025 Vermont Avenue, NW
Suite 1120
Washington, DC 20005
(800) 850-4726 or (202) 638-4101
Fax: (202) 638-7257
info@parkinsonsaction.org
<http://www.parkinsonsaction.org>

Non-profit education and advocacy organization that serves as a voice for the Parkinson's community by fighting for promising research that will produce effective treatments and a cure.

Parkinson's Disease Foundation (PDF)

1359 Broadway
Suite 1509
New York, NY 10018
(212) 923-4700 or (800) 457-6676
Fax: (212) 923-4778
info@pdf.org
<http://www.pdf.org>

National nonprofit organization that supports Parkinson's disease research, patient education, and public advocacy programs.

RESOURCE LIST

Parkinson's Institute

1170 Morse Avenue
Sunnyvale, CA 94089-1605
(408) 734-2800 or (800) 786-2958
Fax: (408) 734-8522
<http://www.thepi.org>

Non-profit organization conducting patient care and research activities in the neurological specialty area of movement disorders.

Parkinson's Resource Organization

74-090 El Paseo
Suite 102
Palm Desert, CA 92260-4135
(760) 773-5628 or (310) 476-7030 or (877) 775-4111
Fax: (760) 773-9803
info@parkinsonsresource.org
<http://www.parkinsonsresource.org>

Helps families affected by Parkinson's by offering emotional and educational support programs, publishing a monthly newsletter about quality of life and family issues, providing information and referral services, promoting advocacy and public awareness, and providing respite for family caregivers.

WE MOVE (Worldwide Education & Awareness for Movement Disorders)

204 West 84th Street
New York, NY 10024
(212) 875-8312 or (866) 546-3136
Fax: (212) 875-8389
wemove@wemove.org
<http://www.wemove.org>

WE MOVE provides movement disorder information and educational materials to physicians, patients, the media, and the public.

Bachmann-Strauss Dystonia & Parkinson Foundation

Mt. Sinai Medical Center One Gustave L. Levy Place
P.O. Box 1490
New York, NY 10029
(212) 241-5614
Fax: (212) 987-0662
Bachmann.Strauss@mssm.edu
<http://www.dystonia-parkinsons.org>

Non-profit foundation that supports patients, family members, researchers, clinicians, and volunteers working in partnership to find better medical treatments and a cure for dystonia and Parkinson's disease.

Peripheral Arterial Disease (PAD)

Peripheral Arterial Disease *NIH* (National Heart, Lung, and Blood Institute)
http://www.nhlbi.nih.gov/health/dci/Diseases/pad/pad_what.html

Stay in Circulation: Take Steps to Learn About PAD
<http://www.nhlbi.nih.gov/health/public/heart/pad/index.html>

Peripheral Arterial Disease Coalition
<http://www.padcoalition.org/wp/>

RESOURCE LIST

Peripheral Vascular Disease (American Heart Association)
<http://www.americanheart.org/presenter.jhtml?identifier=4692>

Peripheral Arterial Disease (Mayo Foundation for Medical Education and Research)
<http://www.mayoclinic.com/health/peripheral-arterial-disease/DS00537>

Peripheral Arterial Disease (PAD) and Limb Loss (Amputee Coalition of America)
http://www.amputee-coalition.org/easyread/fact_sheets/dysvascular-ez.html

Rheumatoid Arthritis (RA)

National Institute of Arthritis and Musculoskeletal and Skin Diseases

National Institutes of Health
1 AMS Circle
Bethesda, MD 20892-3675
(301) 495-4484 or
(877) 22-NIAMS (226-4267)
Fax: (301) 718-6366
TTY: (301) 565-2966
niamsinfo@mail.nih.gov
<http://www.niams.nih.gov/>

The National Institute of Arthritis and Musculoskeletal and Skin Diseases provides information about various forms of arthritis and rheumatic diseases. It distributes patient and professional education materials and also refers people to other sources of information.

The National Institute of Allergy and Infectious Diseases

National Institutes of Health
Building 31, Room 7A50
31 Center Drive, MSC 2520
Bethesda, MD 20892-2520
(301) 496-5717
Fax: (301) 402-0120
www.niaid.nih.gov

The National Institute of Allergy and Infectious Diseases conducts and supports research that strives to understand, treat, and ultimately prevent the myriad infectious, immunologic, and allergic diseases that threaten hundreds of millions of people worldwide. The Institute's mission is driven by a strong commitment to basic research and the understanding that the fields of immunology, microbiology, and infectious disease are related and complementary.

National Center for Complementary and Alternative Medicine

NCCAM Clearinghouse
P.O. Box 7923
Gaithersburg, MD 20898-7923
(301) 519-3153 or
(888) 644-6226
Fax: (866) 464-3616
TTY: (866) 464-3615
www.nccam.nih.gov

The National Center for Complementary and Alternative Medicine is dedicated to exploring complementary and alternative healing practices in the context of rigorous science, training complementary and alternative medicine researchers, and disseminating authoritative information to the public and professionals.

RESOURCE LIST

American Academy of Orthopaedic Surgeons (AAOS)

P.O. Box 2058
Des Plaines, IL 60017
(800) 824-BONE (2263)
www.aaos.org

The Academy provides education and practice management services for orthopaedic surgeons and allied health professionals. It also serves as an advocate for improved patient care and informs the public about the science of orthopaedics. The orthopaedist's scope of practice includes disorders of the body's bones, joints, ligaments, muscles, and tendons. For a single copy of an AAOS brochure, send a self-addressed, stamped envelope to the address above or visit the AAOS Web site.

American College of Rheumatology

1800 Century Place, Suite 250
Atlanta, GA 30345
(404) 633-3777
Fax: (404) 633-1870
www.rheumatology.org

The College provides referrals to rheumatologists and physical and occupational therapists who have experience working with people who have rheumatoid arthritis. The organization also provides educational materials and guidelines.

Arthritis Foundation

P.O. Box 7669
Atlanta, GA 30357-0669
(404) 872-7100 or (800) 568-4045 or your local chapter, listed in the telephone directory
www.arthritis.org

The Arthritis Foundation is the major voluntary organization devoted to supporting arthritis research and providing educational and other services to individuals with arthritis. The Foundation publishes a free pamphlet on rheumatoid arthritis and a magazine for members on all types of arthritis. It also provides up-to-date information on research and treatment, nutrition, alternative therapies, and self-management strategies. Chapters nationwide offer exercise programs, classes, support groups, physician referral services, and free literature.

Scleroderma

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

National Institutes of Health
1 AMS Circle
Bethesda, MD 20892-3675
(301) 495-4484 or (877) 22-NIAMS (226-4267)
TTY: (301) 565-2966
Fax: (301) 718-6366
NIAMSInfo@mail.nih.gov
www.niams.nih.gov

NIAMS provides information about various forms of arthritis and other rheumatic diseases, as well as other bone, muscle, joint, and skin diseases. It distributes patient and professional education materials and refers people to other sources of information. Additional information and updates can also be found on the NIAMS Web site.

American Academy of Dermatology

P.O. Box 4014
Schaumburg, IL 60168-4014
(888) 462-DERM (3376)
Fax: (847) 240-1859
www.aad.org

This national professional association for dermatologists publishes a pamphlet on skin conditions and can also provide physician referrals.

RESOURCE LIST

American College of Rheumatology

1800 Century Place, Suite 250

Atlanta, GA 30345

(404) 633-3777

Fax: (404) 633-1870

www.rheumatology.org

This association provides referrals to doctors and health professionals who work on arthritis, rheumatic diseases, and related conditions. It also provides educational materials and guidelines.

Scleroderma Foundation

300 Rosewood Drive, Suite 105

Danvers, MA 01923

(978) 463-5843 or (800) 722-HOPE (4673)

(8:30 a.m.–5:00 p.m. ET, Monday–Friday)

Fax: (978) 463-5809

sfinfo@scleroderma.org

www.scleroderma.org

This voluntary organization publishes information on scleroderma and funds research. It also offers patient education seminars, support groups, physician referrals, and information hotlines.

Scleroderma Research Foundation

220 Montgomery Street, Suite 1411

San Francisco, CA 94104

(415) 834-9444 or (800) 441-CURE (2873)

Fax: (415) 834-9177

www.srfcure.org

The foundation's goal is to find a cure for scleroderma by funding and facilitating the most promising, highest quality research and by placing the disease and its need for a cure in the public eye. The foundation distributes patient handbooks and a twice yearly, research-related newsletter.

Arthritis Foundation

P.O. Box 7669

Atlanta, GA 30357-0669

(404) 872-7100 or (800) 568-4045 or call your local chapter (listed in the telephone directory)

www.arthritis.org

This is the main voluntary organization devoted to all forms of arthritis and rheumatic diseases. The foundation offers free information about scleroderma on its Web site.

Stroke

National Institute of Neurological Disorders and Stroke

Brain Resources and Information Network (BRAIN)

P.O. Box 5801

Bethesda, MD 20824

(800) 352-9424

<http://www.ninds.nih.gov>

American Stroke Association: A Division of American Heart Association

7272 Greenville Avenue

Dallas, TX 75231-4596

(888) 4STROKE (478-7653)

Fax: (214) 706-5231

strokeassociation@heart.org

<http://www.strokeassociation.org>

RESOURCE LIST

National Stroke Association

9707 East Easter Lane; Suite B
Centennial, CO 80112-3747
(303) 649-9299 or
(800) STROKES (787-6537)
Fax: (303) 649-1328
info@stroke.org
<http://www.stroke.org>

National Rehabilitation Information Center (NARIC)

4200 Forbes Boulevard; Suite 202
Lanham, MD 20706-4829
(301) 459-5900 or (301) 459-5984 (TTY)
(800) 346-2742
Fax: (301) 562-2401
naricinfo@heitechservices.com
<http://www.naric.com>

Stroke Clubs International

805 12th Street
Galveston, TX 77550
(409) 762-1022
strokeclubs@earthlink.net

Easter Seals

230 West Monroe Street
Suite 1800
Chicago, IL 60606-4802
(312) 726-6200 or (800) 221-6827
Fax: (312) 726-1494
info@easterseals.com
<http://www.easterseals.com>

National Aphasia Association

350 Seventh Avenue
Suite 902
New York, NY 10001
(212) 267-2814 or (800) 922-4NAA (4622)
Fax: (212) 267-2812
naa@aphasia.org
<http://www.aphasia.org>

American Speech-Language-Hearing Association (ASHA)

10801 Rockville Pike
Rockville, MD 20852-3279
(800) 638-8255
(301) 571-0457
actioncenter@asha.org
<http://www.asha.org>

Traumatic Brain Injury (TBI)

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN

P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424
<http://www.ninds.nih.gov>

Information also is available from the following organizations:

Acoustic Neuroma Association

600 Peachtree Parkway
Suite 108
Cumming, GA 30041
(770) 205-8211 or (877) 202-0239
Fax: (770) 205-0239 or (877) 202-0239
info@anausa.org
<http://www.anausa.org>

Provides information and support to patients diagnosed with or treated for acoustic neuroma or other benign tumors affecting the cranial nerves.

RESOURCE LIST

Brain Injury Association of America, Inc.

8201 Greensboro Drive
Suite 611
McLean, VA 22102
(703) 761-0750 or (800) 444-6443
Fax: (703) 761-0755
FamilyHelpline@biausa.org
<http://www.biausa.org>

Non-profit organization dedicated to people with brain injury and their families. Offers research, education, and advocacy programs through a national office, network of state affiliates, support groups, and a helpline.

Brain Trauma Foundation

523 East 72nd Street
8th Floor
New York, NY 10021
(212) 772-0608
Fax: (212) 772-0357
<http://www.braintrauma.org>

Nationwide organization devoted to improving the outcome of traumatic brain injury patients. Focuses on the acute phase of traumatic brain injury (TBI) and methods to improve chances of a meaningful recovery. The Foundation works to improve the care of TBI patients from the scene of injury to the emergency room and ICU through guidelines development, professional education, quality improvement, and clinical research.

Family Caregiver Alliance/ National Center on Caregiving

180 Montgomery Street
Suite 1100
San Francisco, CA 94104
(415) 434-3388 or (800) 445-8106
Fax: (415) 434-3508
info@caregiver.org
<http://www.caregiver.org>

Supports and assists families and caregivers of adults with debilitating health conditions. Offers programs and consultation on caregiving issues at local, state, and national levels. Offers free publications and support online, including a national directory of publicly funded caregiver support programs.

National Stroke Association

9707 East Easter Lane
Suite B
Centennial, CO 80112-3747
(303) 649-9299 or (800) STROKES (787-6537)
Fax: (303) 649-1328
info@stroke.org
<http://www.stroke.org>

National non-profit organization that offers education, services and community-based activities in prevention, treatment, rehabilitation and recovery. Serves the public and professional communities, people at risk, patients and their health care providers, stroke survivors, and their families and caregivers.

National Rehabilitation Information Center (NARIC)

4200 Forbes Boulevard
Suite 202
Lanham, MD 20706-4829
(301) 459-5900 or (301) 459-5984 (TTY) or (800) 346-2742
Fax: (301) 562-2401
naricinfo@heitechservices.com
<http://www.naric.com>

RESOURCE LIST

National Institute on Disability and Rehabilitation Research (NIDRR)

U.S. Department of Education Office of Special Education and Rehabilitative Services
400 Maryland Avenue, S.W.
Washington, DC 20202-7100
(202) 245-7460 or (202) 245-7316 (TTY)
<http://www.ed.gov/about/offices/list/osers/nidrr>

Falls Risk

NIH Osteoporosis and Related Bone Diseases~National Resource Center

2 AMS Circle
Bethesda, MD 20892-3676
(202) 223-0344 or
(800) 624-BONE (2663)
TTY: (202) 466-4315
Fax: (202) 293-2356
NIAMSBoneInfo@mail.nih.gov
www.niams.nih.gov/bone

National Institute on Aging (NIA)

Building 31, Room 5C27
31 Center Drive, MSC 2292
Bethesda, MD 20892
(301) 496-1752 or
(800) 222-2225
TTY: (800) 222-4225
Fax: (301) 496-1072
niainfo@nia.nih.gov
www.nia.nih.gov

Don't Let a Fall Be Your Last Trip: Who's at Risk? (American Academy of Orthopaedic Surgeons)
http://orthoinfo.aaos.org/brochure/thr_report.cfm?Thread_ID=21&topcategory=Injury%20Prevention

Why Do We Fall? (American Academy of Otolaryngology--Head and Neck Surgery)
<http://www.entnet.org/healthinfo/balance/fall.cfm>

Falls and Fractures *NIH* (National Institute on Aging) <http://www.niapublications.org/agepages/falls.asp> Also available in Spanish

Falls and Older Adults *NIH Senior Health* (National Institute on Aging) <http://nihseniorhealth.gov/falls/toc.html>

What Are Ways to Prevent Falls and Related Fractures? *Easy-to-Read NIH* (National Institute of Arthritis and Musculoskeletal and Skin Diseases) http://www.niams.nih.gov/bone/hi/ff_falls_prevention.htm

San Diego's Fall Prevention video

http://sandiego.networkofcare.org/aging/library/fall_prevention.cfm