The following is an alphabetical compilation of organizations listed in the Resources section of the main body entries. Although the list is comprehensive, it is by no means exhaustive. It is a starting point for gathering further information. Many of the organizations listed provide information for multiple disorders and have links to additional related websites. Email addresses and web addresses listed were provided by the associations; Thomson Gale is not responsible for the accuracy of the addresses or the contents of the websites.

Sp–Society
7100 Katella Ave. #502
Stanton, CA 90680
Phone: (888) 970-0777
Website: http://www.fivepminus.org

22q13 Deletion Syndrome Foundation
250 East Broadway
Maryville, TN 37804
Phone: (800) 932-2943
Website: http://www.22q13.com

A-T Children’s Project
668 South Military Trail
Deerfield Beach, FL 33442
Phone: (800) 5-HELP-A-T
Website: http://www.atcp.org

A-T Medical Research Foundation
5241 Round Meadow Road
Hidden Hills, CA 91302
Website: http://www.pathnet.medsch.ucla.edu/people/faculty/gatti/gatsign.htm

AboutFace International
123 Edwards Street, Suite 1003
Toronto, ON M5G 1E2
Canada
Phone: (800) 665-FACE
E-mail: info@aboutfaceinternational.org
Website: http://www.aboutfaceinternational.org

AboutFace USA
PO Box 458
Crystal Lake, IL 60014
Phone: (312) 337-0742 or (888) 486-1209
E-mail: aboutface2000@aol.com
Website: http://www.aboutface2000.org

Achromatopsia Network
C/O Frances Futterman
PO Box 214
Berkeley, CA 94701-0214
Website: http://www.acromat.org/how_to_join.html

Acid Malate Deficiency Association
(AMDA)
PO Box 700248
San Antonio, TX 78270-0248
Phone: (210) 494-6144 or (210) 490-7161
Fax: (210) 490-7161 or (210) 497-3810
Website: http://www.amda-pompe.org

Agenesis of the Corpus Callosum
(ACC) Network
University of Maine
Merrill Hall, Room 18, 5749
Orono, ME 04469-5749
Phone: (207) 581-3119
E-mail: um-acc@maine.edu

Aicardi Syndrome Awareness and Support Group
29 Delavan Ave.
Toronto, ON M5P 1T2
Canada
Phone: (416) 481-4095

Academy of Special Education 
AIDS Foundation
450 Waterwood Dr.
Roselle, IL 60172
Phone: (800) 373-8518.
Website: http://www.aicardi.com

AIC Support Group (AISBG)
PO Box 269, Bambury
Oxon, OX15 6YT
United Kingdom
Website: http://www.medhelp.org/www/ais

AKU Hotline
Website: http://www.goodnet.com/~ee72478/enable/hotline.htm

Alcoholics Anonymous World Services
PO Box 459, Grand Central Station
New York, NY 10163
Phone: (212) 870-3400

Alexander Graham Bell Association
for the Deaf, Inc.
3477 Volta Place NW
Washington, DC 20007-2778.
Phone: (800) 432-7543
Website: http://www.agueb.org

Allergy and Asthma Network,
Mothers of Asthmatics, Inc.
2731 Prosperity Ave., Suite 150
Fairfax, VA 22031
Phone: (800) 878-4403
Fax: (703) 573-7794

Alliance of Genetic Support Groups
4301 Connecticut Ave. NW, Suite 404
Washington, DC 20008

Gale Encyclopedia of Genetic Disorders 2 1385
Alpha 1 National Association
8120 Penn Ave. South, Suite 549
Minneapolis, MN 55431
Phone: (612) 703-9979 or (800) 521-3025
E-mail: julie@alpha1
Website: http://www.alpha1.org

Alpha One Foundation
2937 SW 27th Ave., Suite 302,
Miami, FL 33133.
Phone: (305) 567-9888 or (877) 228-7321.
E-mail: mserven@alphaone.
Website: http://www.alphaone.org

Alpha to Alpha
RR#5 Box 859
Warsaw, MO 65355
Phone: (660) 438-3045
Website: http://www.alpha2alpha.org

AlphaNet
Phone: (800) 557-2638
Website: http://www.alphanet.org

American Academy of Allergy,
Asthma & Immunology
611 E. Wells Street
Milwaukee, WI 53202
Phone: (414) 272-6071
Fax: (414) 272-6070
Website: http://www.aaaai.org

American Academy of Dermatology
PO Box 4014, 930 N. Meacham Road
Schaumburg, IL 60168-4014
Phone: (847) 330-0230
Fax: (847) 330-0050
Website: http://www.aad.org

American Academy of Ophthalmology
PO Box 7424
San Francisco, CA 94120-7424
Phone: (415) 561-8500
Website: http://www.eyenet.org

American Academy of Orthopaedic Surgeons
P.O. Box 2058
Des Plaines, IL 60017
Phone: (800) 824-2263
Website: http://www.aaos.org

American Academy of Pediatrics
141 Northwest Point Boulevard
Elk Grove Village, IL 60007-1098
Phone: (847) 434-4000
Fax: (847) 434-8000
Website: http://www.aap.org/visit/contact.htm

American Association for Ambiguous Genitalia Support Network
PO Box 713
Clemmons, CA 95227-0313
Phone: (209) 727-0313
Fax: (209) 727-0313
E-mail: agsn@jps.net
Website: http://www.agsn.org

American Association for Pediatric Ophthalmology and Strabismus
Website: http://med-aapos.bu.edu/

American Association of the Deaf-Blind
814 Thayer Ave., Suite 302
Silver Spring, MD 20910
Phone: (301) 588-6545, (301) 495-4403
TTY Phone: (301) 495-4402
Fax: (301) 495-4404
Email: info@aad.org
Website: http://www.aad.org

American Association of Kidney Patients
3505 E. Frontage Rd., Ste. 315
Tampa, FL 33617-1796
Phone: (800) 749-2257, (813) 636-8100
Fax: (813) 636-8122
Email: info@aakp.org
Website: http://www.aakp.org

American Association on Mental Retardation (AAMR)
444 North Capitol Street NW, Suite 1000
Washington, DC 20001-1512
Phone: (800) 424-3688.
Website: http://www.aamr.org

American Cancer Society
1599 Clifton Road NE
Atlanta, GA 30329
Phone: (800) 227-2345
Website: http://www.cancer.org

American Cleft Palate-Craniofacial Association
104 South Estates Dr., Suite 204
Chapel Hill, NC 27514
Phone: (919) 993-9044
Fax: (919) 933-9604
Website: http://www.cleftline.org

American College of Obstetricians and Gynecologists
PO Box 96020, 409 12th Street SW
Washington, DC 20090-6920
Website: http://www.acog.org

American College of Rheumatology
1800 Century Place, Suite 250
Atlanta, GA 30329
Phone: (404) 633-3777
Website: http://www.rheumatology.org

American Council of the Blind
1155 15th Street NW, Suite 720
Washington, DC 20005
Phone: (202) 467-5081 or (800) 424-
Anxiety Disorders Association of America
11900 Parklawn Dr., Suite 100
Rockville, MD 20852
Phone: (301) 231-9350
Fax: (301) 231-7392
E-mail: anxiety@adaa.org

Apert Syndrome Support Group
1935 Eastway
Street Louis, MO 63126
Phone: (314) 965-3356

Aplastic Anemia Foundation
PO Box 613
Annapolis, MD 21404-0613
Phone: (800) 747-2820
Website: http://www.aplastic.org

Arc (A National Organization on Mental Retardation)
1010 Wayne Ave., Suite 650
Silver Spring, MD 20910
Phone: (800) 433-5255
Website: http://www.tharclink.org

Arc of the United States (formerly Association for Retarded Citizens of the US)
500 East Border Street, Suite 300
Arlington, TX 76010
Phone: (817) 261-6003
Website: http://thearc.org

Arc's Fetal Alcohol Syndrome Resource Guide
The Arc's Publication Desk
3300 Pleasant Valley Lane, Suite C,
Arlington, TX 76015
Phone: (888) 368-8009
Website: http://www.thearc.org/misc/faslist.html

Arthritis Foundation
1330 West Peachtree Street
Atlanta, GA 30309
Phone: (800) 283-7800
Website: http://www.arthritis.org

Arthrogryposis Group (TAG)
1 The Oaks
Gillingham
Dorset, SP8 4SW
United Kingdom
Phone: 01747-822655
Website: http://tagonline.uk

Association for Glycogen Storage Disease (United Kingdom)
Phone: 0131 554 2791
Fax: 0131 244 8926
Website: http://www.agsd.org.uk

Association for Frontotemporal Dementias (AFTD)
P.O. Box 7191
St. David's, PA 19887-7191
Email: info@ftd-picks.org
Website: http://www.ftd-picks.org

Association for Macular Diseases, Inc.
210 East 64th Street
New York, NY 10021
Phone: (212) 605-3719
E-mail: 2020@nieh.gov
Website: http://www.macula.org

Association for Neuro-Metabolic Disorders
5223 Brookfield Lane
Sylvania, OH 43560-1809
Phone: (419) 885-1497

Association for Science in Autism Treatment
175 Great Neck Road, Suite 406
Great Neck, NY 11021
Phone: (516) 466-4400
Fax: (516) 466-4484
Email: asat@autism-treatment

Association for Spina Bifida and Hydrocephalus
42 Park Road
Peterborough, PE1 2UQ
United Kingdom
Phone: 01733 535 5988
Fax: 01733 535 5985
E-mail: postmaster@asbah
Website: http://www.asbah.demon.co.uk

Association for the Bladder Exstrophy Community
PO Box 1472
Wake Forest, NC 27588-1472
Phone: (919) 624-9447
Website: http://www.bladderexstrophy.com/support.htm

Association of Birth Defects in Children
950 Woodcock Road, Suite 225
Orlando, FL 32803
Phone: (407) 895-0802
Website: http://www.biethdefects.org

Association Strumpell-Lorrain
7 D rue des Granges, Besancon, Int1
25000, France
Phone: (038) 150 2391
Website: http://www.aslh.org/anglais/english.htm

Asthma and Allergy Foundation of America (AAFA)
1233 20th Street NW, Suite 402
Washington, DC 20036
Phone: (800) 7-Asthma
Fax: (202) 466-8940
Website: http://www.aafa.org

The A-T Project
3002 Enfield Road
Austin, TX 78703
Phone: (512) 472-4892
Website: http://www.atproject.org

Ataxia MJD Research Project, Inc.
875 Mahler Road, Suite 161
Burlington, CA 94010-1621
Phone: (650) 259-3984
Fax: (650) 259-3983
Website: http://www.ataxiamjd.org

Autism Research Institute
4182 Adams Ave.
San Diego, 92116
Fax: (619) 563-6840

Autism Society of America
7910 Woodmont Ave. Suite 300
Bethesda, MD 20814-3015
Phone: (301) 657-0881 or (800) 3-AUTISM
Website: http://www.autism-society.org

AVENUES National Support Group for Arthrogryposis Multiplex Congenita
PO Box 5192
Sonora, CA 95370
Phone: (209) 928-3688
Email: avensue@sonnet.com
Website: http://www.sonnet.com/avenues

Bachmann-Strauss Dystonia & Parkinson Foundation, Inc.
Mount Sinai Medical Center, One Gustave L. Levy Place, Box 1490
New York, NY 10029
Phone: (212) 241-5614
Website: http://www.dystonia-parkinsons.org
Achondroplasia, 1: 19–23, 1: 21, 1: 22, 1: 500, 1: 592
autosomal-dominant inheritance, 1: 685–686
fibroblast growth factor receptor 1, 1: 467–468, 1: 468;
Achondroplasia, 1: 197, 1: 261
acral pseudosyndactyly, 2: 1077
ACHRO syndrome, 1: 23–25, 1: 24
Achromatoplasia, 1: 274–275
Acriflavine, 1: 1355
Acid maltase deficiency, 2: 928
Acidiphilic chondroplasia, 1: 685
Acidosis, 2: 956, 2: 957, 2: 958, 2: 959
Acinetobacter, 1: 575–576, 1: 756, 1: 757
Acipenser, 1: 516
Acne, 1: 496–499
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Acne rosacea, 1: 576
Acne vulgaris, 1: 576
Acneiform eruptions, 1: 496
Alpha thalassemia mental retardation syndrome, 2: 1251–1252
Alpha thalassemia trait, 2: 1249
Alpha-1 antitrypsin, 1: 59, 64–66, 1: 159
Alpha-1 antitrypsin deficiency, 2: 159–164
Alpha-1 antitrypsin protein, 1: 67, 1: 484
Alpha-amidation
Alzheimer disease, 1: 67, 1: 484
Alzheimer, Alois, 1: 67, 1: 484
Aluminum-containing antacids, 2: 1193
Alternative treatments
Alsin gene, 1: 622
Aluminum-neuraminidase deficiency. See Neuraminidase deficiency
Alpha-thalassemia X-linked mental retardation syndrome, 1: 66
Neuraminidase deficiency
See Neuraminidase deficiency
Alpha-N-acetylneuraminidase, 2: 901, 2: 905
Alpha-mannosidosis, 2: 780, 2: 781
Alpha-L-iduronidase, 2: 830, 2: 834, 2: 835
Alpha-galactosidase A, Fabry disease
Alpha-fetoprotein (AFP), 1: 75
Alpha/beta blockers, for essential hypertension
Alpha-1 antitrypsin protein
See Also Maternal serum alpha-fetoprotein test
Alpha-galactosidase A, Fabry disease
Amelogenesis imperfecta, 1: 277
Amyotrophic lateral sclerosis
Congenita, 1: 111
Alpha-L-iduronidase, 2: 830, 2: 833, 2: 834, 2: 835
Alpha-mannosidosis, 2: 780, 2: 781
Alpha-N-acetylmuramidase, 2: 901, 2: 905
Alpha-neuraminidase deficiency. See Neuraminidase deficiency
Alpha-thalassemia X-linked mental retardation syndrome, 1: 66–67, 1: 1201
ALPS, gene, 2: 1197
Alport syndrome, 1: 452–456, 1: 609, 1: 610, 1: 611, 1: 612
ALS. See Amyotrophic lateral sclerosis
Alion gene, 1: 622
Alternative treatments
arthrogryposis multiplex congenita, 1: 111
cancer, 1: 205
cystic fibrosis, 1: 321
dystonia, 1: 384
Edwards-Daños syndrome, 1: 407
multiple sclerosis, 2: 858
myopia, 2: 877
osteogenesis imperfecta, 2: 962
Parkinson disease, 2: 991
porphyria, 2: 1050–1051
rickets, 2: 1186
Altmann, Richard, 1: 364
Aluminum-containing amalgams, 1: 377
osteoradionecrosis from, 2: 963
Alzheimer, Alois, 1: 67, 1: 484
Alzheimer disease, 1: 67–72, 1: 69, 1: 70
color blindness from, 1: 273
as dementia, 1: 336, 1: 357
diagnosis, 1: 69–70, 1: 339
vs. frontotemporal dementia, 1: 486, 1: 487
presymptomatic testing, 1: 530
Amyotrophic for Friedrich ataxia, 1: 481
for Parkinson disease, 2: 990
Ambiguous genitalia, 1: 610, 1: 612
Ammonia, 1: 72–75
Amelogenesis imperfecta, 1: 277
American Academy of Child and Adolescent Psychiatry (AACAP), 1: 132
American Academy of Neurology, 1: 487
American Academy of Pediatrics, 2: 1021
American Cancer Society (ACS) cancer screening, 1: 203
cancer signs, 1: 202
gastric cancer, 1: 498, 1: 500
liver cancer, 1: 596
Pap smears, 1: 389
prostate cancer, 2: 1070, 2: 1072
American College of Medical Genetics,
American College of Obstetricians and Gynecologists (ACOG)
amnioncentesis, 1: 76
Canavan disease, 1: 197
premature ultrasound, 2: 1056–1057
American Diabetes Association, 1: 351–352
American Heart Association, 1: 286
American Journal of Medical Genetics, 1: 197
American College of Obstetricians and Gynecologists (ACOG)
amnioncentesis, 1: 76
Canavan disease, 1: 197
premature ultrasound, 2: 1056–1057
American Diabetes Association, 1: 351–352
American Heart Association, 1: 286
American Institute of Ultrasound Medicine Bioeffects Committee, 2: 1056
American Journal of Medical Genetics, 1: 1209
American Optical/Hardy, Rand, and Titter Pseudoisochromatic test, 1: 275
American Society for Chromosome Research
Amino acids dibasic, 1: 325, 1: 326
metabolism disorders, 2: 946–949, 2: 1019–1024
methylmalonic CoA mutase deficiency and, 2: 816
for Parkinson disease, 2: 991
Amino aciduria for nephrogenic diabetes insipidus, 2: 893
aminolevulinic aciduria, 1: 321
Aminoglycosides, hearing loss from, 2: 1019–1024
Aminoimidazole carboxylase, for pernicious anemia, 2: 955–956
Aminoimidazole carboxylase, for pernicious anemia, 2: 955–956
Aminoglycoside antibiotics, 1: 321
Aminoglycosides, hearing loss from, 1: 612
Aminopterin syndrome sine amnioncentesis, 1: 306
Amipitriptyline for depression, 1: 346
for rheumatoid arthritis, 2: 1121
AML (Acute myelogenous leukemia), 1: 458, 1: 746, 2: 993
AMN (Adrenomyeloneuropathy), 1: 35, 1: 37
Aminocitrate, 1: 75–81, 1: 79, 1: 531
acanthoendothelioma, 2: 21
adrenoleukodystrophy, 1: 37
aftercare, 1: 532
alpha-thalassemia X-linked mental retardation syndrome, 1: 66
ApoE genotype, 1: 302
ApoE genotype
Aneuploidy, 1: 148
biodistribution deficiency, 1: 165
vs. chorionic villus sampling, 1: 78
chromosomal abnormalities, 1: 254
clubfoot, 1: 262
congenital adrenal hyperplasia, 1: 281
cystinosis, 1: 323
delletion 22q11 syndrome, 1: 334
dentatorubral-pallidoluysian atrophy, 1: 342–343
Down syndrome, 1: 372–373
ectodactyly-ectodermal dysplasia-clefting syndrome, 1: 403
Elders-Daños syndrome
kyphoscoliosis type, 1: 406
euphyrophosphonates, 2: 117
cystic fibrosis, 1: 417
facioscapulohumeral muscular dystrophy, 1: 437
fragile X syndrome, 1: 474
gene counseling, 1: 520
genic counseling, 1: 520
GM1-gangliosidosis, 1: 557
harlequin fetus, 1: 580
hemophilia, 1: 594
hypochondrogenesis, 1: 660
hypophosphatemia, 1: 662–663
hypophosphatemia, 1: 666, 1: 667
ichthyosis, 1: 674
infantile Refsum disease, 1: 683
Kienboe syndrome, 1: 716
Kniebel syndrome, 1: 724
Kleindienst syndrome, 1: 739–740
Menkes syndrome, 2: 807, 2: 808
miscarriages with, 1: 76, 1: 78–79, 1: 343, 1: 373, 1: 382, 1: 1185, 1: 1291
mucoepidermoid carcinoma type I, 2: 835
myoclonic dystrophy, 2: 880
neurofibromatosis, 2: 910
ophthalmic, 2: 935
Optx, 1: 943
osteogenesis imperfecta, 2: 961
Pellegrino-Merzbacher disease, 1: 1001
Pefazz-Zegers syndrome, 2: 1012
Pfeiffer syndrome, 2: 1127
Peutz-Jeghers syndrome, 1: 1036
Pfister-Willis syndrome, 2: 1054
propios/asocumented, 2: 1066
pseudoacanthoendothelioma, 2: 1078
Refsum disease, 2: 1098
rhizomelic chondrodysplasia, 1: 1127
Rieger syndrome, 2: 1127