CHARGE SYNDROME RESOURCES

Compiled by: Wendy Keedy and Betsy McGinnity

CHARGE Syndrome Foundation, Inc.
2004 Parkade Blvd.
Columbia, MO 65202-3121
phone: (800)442-7604 Parent line (USA callers only)
(573)499-4694 all others
FAX: (573)499-4694
e-mail: marion@chargesyndrome.org
http://www.chargesyndrome.org

**INTERNATIONAL CHARGE ORGANIZATIONS**

CHARGE Family Support Group
82 Gwendolen Ave
London E13 0RD
United Kingdom
phone: (01)020 8552 6961
http://www.widerworld.co.uk/charge/

The Australasian CHARGE Association
P.O. Box 91
Glenfield, N.S.W. 2167
Australia
phone: (02) 9829-4801
e-mail: austcharge@hotmail.com

Queensland CHARGE Association
16 Ronmack Street
Chermside QLD 4032
Australia
phone: (07)3359-6297
e-mail: charge_qld@hotmail.com
http://www.users.bigpond.com/arrone/

** CHARGE WEB PAGE and LISTSERVE**

CHARGE Syndrome Foundation, Inc.
http://www.chargesyndrome.org

Minnow’s CHARGE WebPage:
http://www.geocities.com/Heartland/1220/
charge@saber.net
**DEAF AND DEAFBLIND RESOURCES**

A.G. Bell Association for the Deaf
3417 Volta Place, N.W.
Washington, DC 20007-2778
phone: (202) 337-5220 (v, TTY)
http://www.agbell.org/

American Society for Deaf Children
PO Box 1510
Olney, MD 20830
Attn: Mr. Ken Silverstein
1-800-942-ASDC Parent line
ASDC1@aol.com
http://www.deafchildren.org/

DB-LINK, The National Information Clearinghouse on Children who are Deaf-Blind.
(Also lists 307.11 State grantees Deaf-Blind projects)
Teaching Research
345 N. Monmouth Ave.
Monmouth, OR 97361
phone: (800)438-9376 (voice), (800)854-7013 (TTY), FAX: (503)838-8150
e-mail: dblink@tr.wou.edu
http://www.tr.wou.edu/dblink/index.htm

Deafblindness Web Resource
http://www.deafblind.co.uk
Includes terminology, communication, journals, periodicals

The Family Centre
86 Cleveland Road
Ealing, London W13 OHE
United Kingdom
phone: (01)81 991-0513, FAX: (01)81 810-5298

The Foundation for Fighting Blindness
Executive Plaza 1, Suite 800
11350 McCormick Road
Hunt Valley, MD 21031-1014
phone: (800)683-5555 (voice), (800)683-5551 (TTY), FAX: (410) 771-9470
http://www.blindness.org

John Tracy Clinic
806 West Adams Boulevard
Los Angeles, CA 90007
phone: (213) 748-5481 (v), (213) 747-2924 (TTY), (800) 522-4582, FAX: (213) 749-1651
http://www.johntracyclinic.org
Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC)
111 Middle Neck Road
Sand Points, NY 11050-1299
phone: (516) 944-8900 (v), (516) 944-8637 (TTY), FAX: (516) 944-7302
e-mail: abigailp@aol.com
http://www.helenkeller.org/national/index.htm

HOUSE Ear Institute
2100 West 3rd Street
Los Angeles, CA 90057
phone: (800)287-4763 (v, TTY) California, (800)352-8888 (v, TTY) all other 50 states
http://www.hei.org/

Katlyn’s HOPE
303 South Elm Street
Wellington, KS 67152
phone: (316)326-6118, (877)677-HOPE – Toll-free for parents
e-mail: khope@idir.net
http://www.idir.net/~khope/links.html

National Association for Parents of the Visually Impaired, Inc. (NAPVI)
P.O. BOX 317
Watertown, MA 02471
phone: (617) 972-7441, (800) 562-6265, FAX: (617) 972-7444
http://www.spedex.com/napvi

National Coalition on Deaf-Blindness (NCDB)
175 North Beacon Street
Watertown, MA 02472
phone: (617) 972-7347, FAX: (617) 923-8076
e-mail: davies@perkins.pvt.k12.ma.us

National Cued Speech Center
PO Box 31345
Raleigh, NC 27622-1345
phone: (919) 828-1218 (v, TTY)
e-mail: ncsa@aol.com

National Family Association for Deaf-Blind (NFADB)
111 Middle Neck Road
Sand Point, NY 11050
phone: (800) 255-0411, FAX: (516) 944-5984
e-mail: pajomac@aol.com
National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC)
345 N. Monmouth
Monmouth OR 97361
phone: (503) 838-8096 (v) (OR), (503) 838-9623 (TTY) (OR), FAX: (503) 838-8150 (OR),
(516) 944-8900 x 273 (v) (NY), (516) 883-9059 (TTY) (NY), FAX: (516) 883-9060 (NY)
http://www.tr.wou.edu.ntac

NOR-CAL Center on Deafness
Supported Employment Program
1820 Tribune Rd, Suite A
Sacramento, CA 95815
Phone: (916) 921-1045 (v, TTY), FAX: (916) 921-1177

Partners for Progress, Pre-College National Mission Program
Gallaudet University
800 Florida Ave., NE
Washington, DC 20002, FAX: (202) 651-5435
http://www.gallaudet.edu/~parweb/pfp.html

SENSE The National Deafblind and Rubella Association
11-13 Clifton Terrace
Finsbury Park, London N435R
United Kingdom
phone: (01)71 272-7774, FAX: (01)71 272-6012
e-mail: enquiries@sense.org.uk
http://www.vois.org.uk/sense/

U.S. Department of Education Office of Special Education Programs, Division of Education Services For Children with Deaf-Blindness Program
Switzer Bldg., Room 4613
330 C Street, SW
Washington, DC 20202-2734
phone: (202)205-8165, FAX: (202)205-8971
e-mail: charles_freeman@ed.gov

**DEVELOPMENTAL and SENSORY INTEGRATION RESOURCES**

Sandra L.H. Davenport, M.D.
Sensory Genetics/Neuro-Development
5801 Southwood Drive
Bloomington, MN 55437-1739
phone: (952)831-5522 (v, TTY), FAX: (952)831-0381
e-mail: slhdaven@tc.umn.edu
The HANDLE Institute
1530 Eastlake Avenue E., Suite 100
Seattle, WA 98102
phone: (206) 860-2665, FAX: (206) 860-3505
e-mail: support@handle.org
http://www.handle.org

National Academy for Child Development
P.O. BOX 380
Huntsville, UT 84317
phone: (801) 621-8606, FAX: (801) 621-8389
e-mail: nacdinfo@nacd.org
http://www.nacd.org/

Sensory Integration International (SII)
The Ayres Clinic
1514 Cabrillo Avenue
Torrance, CA 90501
phone: (310) 320-2335, FAX: (310) 320-9982
e-mail: sensoryint@earthlink.net
http://home.earthlink.net/~sensoryint/

**DISABILITY RESOURCES**

Beach Center on Families and Disabilities
3111 Haworth Hall
University of Kansas
Lawrence, KS 66045-7516
phone: (913) 864-7600 (v), (913) 864-7600 (TTY) FAX: (913) 864-7605
e-mail: beach@dole.lsi.ukans.edu
http://www.lsi.ukans.edu/beach/beachhp.htm

ERIC Educational Resources Information Center
Clearinghouse on Disabilities and Gifted Children
The Council for Exceptional Children
1920 Association Drive
Reston, VA 20191
phone: (800)328-0272 (v) (703) 264-9449 (TTY)
e-mail: ericec@cec.sped.org
http://www.cec.sped.org/ericec/digests.htm

ESCO Hearing Aid Insurance
Ear Service Corporation
3650 Annapolis Lane, Suite 107
Plymouth, MN 55447
phone: (800) 992-3726
e-mail: info@earserv.com
http://www.earserv.com
MEDICAID Waivers - Katie Beckett Waivers
Health Care Financing Administration (HCFA)
Within the Department of Health and Human Services (DHHS)
Family Voices National Office
PO Box 769
Algodones, NM 87001
Toll-free (888) 835-5669
Voice (505) 867-2368
FAX (505) 867-6517
http://www.familyvoices.org/~vrosales/KATIEBEC.html

NICHCY (National Information Center for Children and Youth with Disabilities)
P.O. BOX 1492
Washington, DC 20013-1492
phone: (800) 695-0285 (v, TTY), 800-695-0285 (v, TTY) FAX: (202)884-8441
http://www.nichcy.org
(Among resources are: State chapters of parent and disability groups, Protection and Advocacy Agencies per State, Parent Training and Information Projects, and IDEA 1997)

NORD (National Organization for Rare Disorders)
100 Rt. 37, P.O. BOX 8923
New Fairfield, CT 06812-8923
phone: (203) 746-6518 (v), (203) 746-6927 (TTY), (800) 999-6673 FAX: (203) 746-6841
e-mail: orphan@nord-rdb.com
http://www.nord-rdb.com/orphan

Special Olympics
1325 G. Street NW, Suite 500
Washington, DC 20005
phone: (202) 628-3630, FAX: (202) 824-0200
http://www.specialolympics.org/

TASH Disability Advocacy Worldwide
29 W. Susquehanna Ave. Baltimore, MD 21204
phone: (410) 828-8274, FAX: (410) 828-6706
e-mail: nweiss@tash.org
http://www.tash.org/

Wide Smiles Web Page

Wright’s Law - The Special Ed Advocate
Peter W.D. Wright, Esq.
P.O. BOX 1008
Deltaville, VA 23043
phone: (804)257-0857
e-mail: webmaster@wrightlaw.com
http://www.wrightlaw.com/
**SPEECH, LANGUAGE AND COMMUNICATION RESOURCES**

American Speech - Language and Hearing Association
10801 Rockville Pike
Rockville, Maryland, 20852
phone: (301) 897-5700 (v), (301) 897-0157 (TTY) FAX: (301) 571-0457
http://www.asha.org/contents.htm

APRAXIA-Kids website
http://www.jump.net/~gmiel/apraxia/

Listenup Web Page Kay Powell
listenup@texas.net
http://members.tripod.com/~listenup/

The Little Room
“Space and Self” book by Lilli Nielsen
Sikon Publisher
http://members.aol.com/LSWebDesgn/LNroom.html

Mayer-Johnson (Picture Communication Symbols)
PO BOX 1579
Solana Beach, California 92075
(800) 588-4548, FAX: (858) 550-0449
http://www.mayerjohnson.com/