

## 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](mailto: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](mailto:austcharge@hotmail.com)

Queensland CHARGE Association  
16 Ronmack Street  
Chermside QLD 4032  
Australia  
phone: (07)3359-6297  
e-mail: [charge\\_qld@hotmail.com](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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: [nscsa@aol.com](mailto:nscsa@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](mailto: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 Tribute Rd, Suite A  
Sacramento, CA 98515

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](mailto: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](mailto: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](mailto: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](mailto: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: [nacinfo@nacd.org](mailto:nacinfo@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](mailto: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  
email: [beach@dole.lsi.ukans.edu](mailto: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](mailto: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](mailto: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](mailto: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](mailto:nweiss@tash.org)  
<http://www.tash.org/>

Wide Smiles Web Page  
<http://www.widesmiles.org/WS-58.html>

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@wrightslaw.com](mailto:webmaster@wrightslaw.com)  
<http://www.wrightslaw.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/~gmikel/apraxia/>

Listenup Web Page Kay Powell  
[listenup@texas.net](mailto: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/>