

Disability Specific Organizations

Autism Society of America - Los Angeles Chapter
Contact person: Caroline Wilson (562) 425-2292
Call for Resources and Information.

Autism Speaks - Los Angeles
5455 Wilshire Boulevard, Suite 2250, Los Angeles, CA 90036
Phone: (323) 549-0500
Fax: (323) 549-0547 <http://www.autismspeaks.org>

Down Syndrome Association of Los Angeles, Inc.
315 Arden Ave., #25, Glendale, CA 91203
Contact Person: Gail Williamson (818) 242-7871
Fax: (818) 242-7819

E-mail: info@dsala.org

Website: <http://www.dsala.org>

Affiliate of the National Down Syndrome Congress and the National Down Syndrome Society; newsletter, peer counseling, meetings, conferences, age specific by-groups, education, information and training.

EK (Exceptional Kids)

3511 W. 187th Street, Torrance, CA 90504

Contact Person: Tom Cash (310) 378-7204

This club is a group for children ages 4 to 16. It offers social and recreation clubs for children with special needs.

(Serves Larson West PAU families)

Epilepsy Foundation of Los Angeles County

5777 W. Century Blvd. Suite 820 Los Angeles, CA 90045

Contact person: Guadalupe Corral-Leyve (800) 564-0445

The Epilepsy Foundation provides information and referral, counseling, emergency I.D. tags and cards, consultation services, parent groups and support networks, educational programs, seminars, materials, community group meetings, and medical and social research.

This group supports individuals of all ages who have a seizure condition and family members. Call the above number for information on support meetings for parents, meetings are both in English and Spanish at various locations in Los Angeles and Orange Counties.

United Cerebral Palsy/Spastic Children's Foundation

Contact person: (818) 782-2211

Information and referral for those who have diagnosed with CP and or a special need birth related. Call for further information regarding parent support groups.

Fragile X Association of Southern California

Contact Person: Diane Bateman (562) 439-1190

E-mail: info@fraxsocal.org

3rd Saturday bi-monthly. Please check for location. Family activities, information and support.

Prader-Willi California Foundation, an Affiliate of Prader-Willi Syndrome, Association (USA)

360 Mobil Avenue, Ste. 205C, Camarillo, CA 93010-6325

Contact Person: Fran Moss (800) 400-9994

Fax: (805) 383-0889

Website: <http://www.pwcf.org>

E-mail: Pwcf@msn.com

Prader-Willi of California provides parents and professionals a state network of information, advocacy and support services to expressly meet the needs of children and adults with PWS and their families. Call the office for newsletter subscriptions and for information regarding annual national conferences.

Rett Syndrome Association (International)

9121 Piscataway Road #2B, Clinton, MD 20735

Contact Person: (301) 856-3334 (800) 818-RETT (7388)

Website: <http://www.rettsyndrome.org>

Publishes a quarterly newsletter which keeps parents and professionals informed of current research in the field and give suggestions for care and management. A family network allows parents to make contact with others whose children are at a similar stage of Rett Syndrome. Also provides annual conference and seminars and publishes a wide variety of information and care materials. Annual membership is \$25 individual, \$30 family, and \$35 international.

Tourette Syndrome Parent Support Group

Contact Person: Loretta Staebler (626) 445-3986

Bob Courdy (714) 995-6261

Offers telephone support and information

Muscular Dystrophy Association Support Group

2800 28th Street suite 153, Santa Monica, CA 90405

Contact Person: Rose Maag (310) 450-9032

Fax: (310) 450-8063

MDA feels strongly about providing emotional support to families touched by neuromuscular disease. Support groups provide a comfortable achievement and success. Caregivers and families, as well as those served by MDA, are all welcome. Call the above number for various groups that meet in Los Angeles, Santa Barbara, Orange Counties and the Inland Empire. One is available in Downey in Spanish.

We Can, Pediatric Brain Tumor Network
P.O. Box 614, Manhattan Beach, CA 90266
Contact Person: Gigi McMillan (310) 739-3433
E-mail: gigi@wecan.cc
Website: <http://www.wecan.cc>
Offers information and emotional support to families who children have brain tumors. We Can sponsors lectures, support group meetings and social events in throughout greater Los Angeles and Orange County.

Neurofibromatosis Family Support Group
2365 Westwood Blvd., Ste #21, Los Angeles, CA 90064
Contact Person: (888) 314-6633
Open to families who have members with neurofibromatosis for information sharing and support. Meetings are scheduled bi-monthly in families' homes. The group is open to anyone who wants to learn about NF. Call Scott for more information.

Betty Clooney Foundation for Persons with Brain Injury
4426 Village Road, Long Beach, CA 90808
Contact Person: (562) 938-9005
The Betty Clooney Foundation host a support group for families and survivors of traumatic brain injury under the auspices of the California Head Injury Foundation, now known as the Brain Injury Association of California. Call for further information or to be added to the mailing lists.

National Sudden Infant Death Syndrome Foundation of Southern California
P.O. Box 90544, Pasadena, CA 91109
Contact Person: (310) 558-4511
24 hour hotline (800) 974-3752
Information, newsletter, monthly meetings; also information and referral to community services. Information available in Spanish. Parent to parent contact, if needed. Services to Los Angeles, San Luis

Obispo, Santa Barbara, and Ventura Counties. Call for information about the various support groups that meet each month.

Low Incidence

Braille Institute of America

741 N. Vermont Ave. Los Angeles, CA 90029

Contact person: (323) 663-1111

Home Service for infants/preschoolers who are visually impaired; there is no center-based program. Parent support group on an as needed basis. For further information regarding parent groups ask for Sue Parker.

Institute for Families of Blind Children

4650 Sunset Blvd. Mailstop 111 Los Angeles, CA 90027

Contact person: Nancy Chernus-Mansfield

(323) 669-4649

Fax: (323) 665-7867

The Institute offers free services to families with a diagnosis of visual impairment along with a newsletter, Parents to Parents Newsletter, Retinoblastoma Support News and videotapes for parents, siblings, and physicians.

Greater Los Angeles Council on Deafness (GLAD)

2222 Laverna Ave., Los Angeles, CA 90041

TTY or Telephone: (323) 478-8000

Fax (323) 550-4205

GLAD Orange County Office

6022 Cerritos Ave. M, Cypress, CA 90630

Contact Person: (714) 826-9793

Fax (714) 826-9813

Interpreter services, peer counseling, advocacy, telephone services, information and referral, recreation and social clubs, sign language class, legal referral. Limited to persons who are deaf or hearing impaired

Spina Bifida Association of Greater Los Angeles

2400 South Flower Street, Los Angeles, CA 90007

Contact person: Sandy Marton, (818) 894-4121

E-mail: sandybear46@hotmail.com

Board meetings are held annually at Orthopedic Hospital. Offers telephone support and information for parents and families of children with Spina Bifida. Activities include fund-raising to help families in financial crisis. The organization receives technical support from Orthopedic Hospital. Support in Spanish is also available. Check out the website: www.spinabifida.org. This will get you into the Spina Bifida Association of America.

Medical Organizations

California Children's Services (CCS)
9320 Telstar Ave., Ste. 226, El Monte, CA 91731-2849
800-288-4584 Fax: 800-924-1154
<http://www.dhcs.ca.gov/services/ccs/Pages/>

California Children's Services (CCS) is a state program for children with certain diseases or health problems. Through this program, children up to 21 years old can get the health care and services they need. CCS will connect you with doctors and trained health care people who know how to care for your child with special health care needs.

Healthy Families

Call: 1-800-880-5305 if you do not already have a child enrolled in Healthy Families. You can ask questions, have the application form sent to you or apply by phone.

<http://www.healthyfamilies.ca.gov/>

Healthy Families is low cost insurance for children and teens. It provides health, dental and vision coverage to children who do not have insurance and do not qualify for free Medi-Cal.

March of Dimes – California

(415) 788-2202

<http://www.marchofdimes.com/>

California Premature Infant Health Coalition

Email: CAPIHC@comcast.net

<http://capihc.blogspot.com/>

The California Premature Infant Health Coalition was created in 2007 to: 1. Create a strong, unified voice in California to help reduce the rate of premature births and improve outcomes for children born prematurely and their families. 2. Provide a sustainable setting to network, share best practice and other information, address policy, resource and systems change, and to help keep decision makers and the general public educated and knowledgeable about prematurity.