

Down Syndrome Association of Los Angeles, Inc.

Aviation Plaza | 16461 Sherman Way, Suite 180 | Van Nuys, CA 91406 | 818-786-0001 | www.dsala.org

connecting families for over 35 years

annual report

october 1, 2010 - september 30, 2011



Leadership Message

The welfare of each is bound up in the welfare of all.
-Helen Keller

Working together *is* success. The DSALA has been fortunate to work together with some of the most dedicated, giving people in Los Angeles for the past 35 years. We are deeply grateful for and celebrate the contributions of all who have come before us, our pioneers and our leaders who have opened the doors for our children, lighting the road to acceptance and understanding.

Together, we have empowered our individuals and have prepared families and the general public to welcome and celebrate the extraordinary lives of people with Down syndrome. More than ever, individuals with Down syndrome are recognized as valuable members of our community. We share with our families and extended communities the praise for this accomplishment.

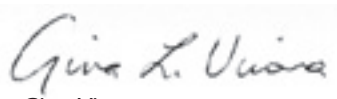
Together, our organization grows ever stronger. At the heart of the DSALA is people. We exist and thrive because of our generous supporters, in-kind donors, caring volunteers, and dedicated staff. Their passion is inspiring.

Together, we will continue our journey, adapting and growing with our community, to be a stronger support, offer resources, and a helping hand.

Looking Forward

1. We offer Saturday Seminars in our community room with a variety of topics such as Down Syndrome Health, Aging with Down Syndrome, Potty Training, Conservatorships, and Anti-bullying.
2. Art Beats: New Experiences in Contemporary Art and Music continues, giving students of all ages expression through painting, clay, photography, and music.
3. Our sports program expands to include more regional areas of Los Angeles.
4. More social events populate our community room.

Our future is truly exciting, with plenty of challenges to overcome and victories to savor. Thank you for sharing your energy and imagination with us as we continue to work for individuals with Down syndrome and their families.



Gina Vivona
President, Board of Directors



Gail Williamson
Director of Programs & Outreach

People First Language

Our People First Language (PFL) defines respectful, accurate communication that recognizes that people with Down syndrome are not their diagnosis or disability. Someone with Down syndrome is a person first - perhaps a co-worker, a sister, a brother, a student. Our child is not a “Down syndrome child” or a “Down’s kid”. He or she may be a child with Down syndrome.

DSALA Board & Staff

2011 Board of Directors

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Jim Hodgson
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& Development

Sandra Baker
Spanish Language
Program Leader,
Office Manager & Family
Support Specialist

DSALA

Connecting Families

For over 35 years the Down Syndrome Association of Los Angeles (DSALA), a non-profit organization, has been a resource center supporting close to 1,800 individuals with Down syndrome and their families.

Our team of dedicated staff and volunteers works tirelessly to:

- Provide members with up-to-date information about Down syndrome. We do this through our website, email blasts, support groups, trainings and conferences.
- Advocate on behalf of individuals at both the local and national levels.
- Train medical professionals and others who work with individuals with Down syndrome so they gain a better understanding of the issues facing our families.
- Enrich the lives of individuals with Down syndrome by promoting opportunities for them to take an active part in their communities.

Our organization is a lifeline for new parents of children with Down syndrome. When they are facing dramatic and unexpected changes to their lives, we connect them to other families, and to community organizations that provide support, as well as vital information on educational, medical and community services. Our Peer Counseling Service offers comfort and optimism to approximately 80 new families annually.

A History of Dedication and Success

What began as a small effort on behalf of a few children has changed the lives of thousands of children and adults with Down syndrome and their families. As recently as 1975, parents of children with Down syndrome were receiving such poor or negative information about their children’s future, that it was still common to place their children in an institution.

A group of 15 committed parents formed the Down Syndrome Association of Los Angeles to find ways to raise their children at home. Their goal was to shift the focus from what was deemed negative about individuals with Down syndrome to focusing on what they could achieve.

Now 35 years later, our primary focus remains unchanged - to enhance the lives of both children and adults with Down syndrome and to support their families. From modest beginnings with 15 families, our staff and volunteers at DSALA served close to 1800 families in 2011.

awareness

Mission Statement

The primary mission of the Down Syndrome Association of Los Angeles is to enhance the welfare of people with Down syndrome and their families through the development and promotion of education, counseling, employment and recreational programs. We strive to increase public awareness, understanding and acceptance of Down syndrome.

What is Down Syndrome?

One in every 671 children is born with Down syndrome, according to the U.S. Center for Disease Control and Prevention. It is the most common, survivable genetic difference. Also called Trisomy 21, it is caused by an extra copy of the 21st chromosome. Researchers have identified the gene on the extra 21st chromosome that is responsible for cognitive delay.

In 1866 an English doctor, John Langdon Down, published a description of the condition which later took his name.

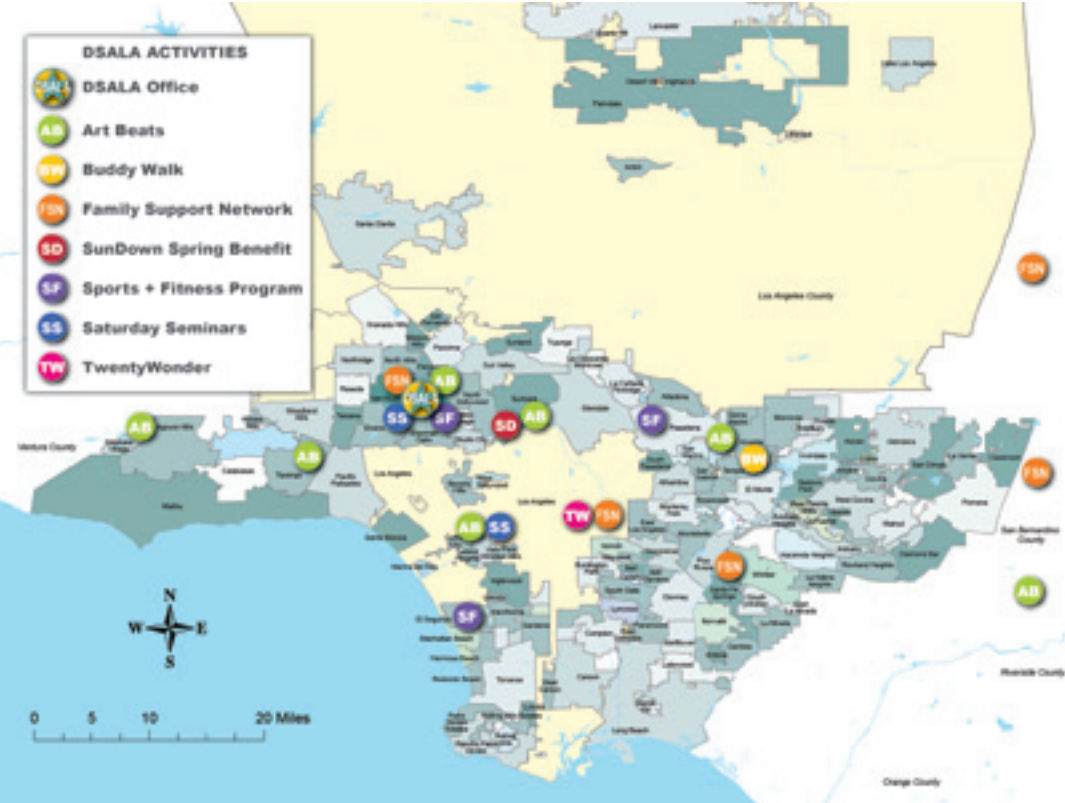
We already know that most people with Down syndrome will live happy and productive lives. Most learn to read, care for themselves, have meaningful jobs and significant others. Advances in healthcare have helped many live well into their 70's.

Now we are optimistic that further research will produce medication that allows them to strengthen their cognitive abilities and lead even fuller lives than is possible today.



Greater Los Angeles Area

The metropolitan area of Los Angeles extends about 60 miles inland from the Pacific coast and consists of hundreds of cities and suburbs linked together by a massive system of freeways. The sheer size of Los Angeles poses an immense challenge to groups like DSALA that want to unite its many neighborhoods for a common cause.



This map shows our growth as we're reaching our communities.

Parent Groups supported by DSALA

Community groups allow our members to connect. These groups are led by active members who volunteer their time and talents to hold educational meetings, social gatherings, and act as a conduit to DSALA happenings.

Up For Down in the Inland Valley

Amor y Fortaleza Los Angeles group for infants to age 5

Amor y Fortaleza San Fernando Valley group for infants to age 3

Crystal Cuevas East Los Angeles

Cultivar y Crecer for parents of children of all ages

VIP High Desert Support Group, Victorville

San Fernando Valley Santa Barbara County Whittier

growth

Public Awareness

One of our goals at DSALA is to increase public awareness, understanding and acceptance of Down syndrome. We provide up-to-date information to hospitals and individuals in both English and Spanish. We offer services to the Family Support Network and Parent Support groups throughout Los Angeles county. Our extensive Resource and Referral Center is full of practical information gathered directly from the experience of families of children with Down syndrome.

Our data point to a need for greater support for families of adults with Down syndrome. As the population ages, adult siblings are becoming the primary caretakers. We are developing support for them through our Saturday Seminars and our Yahoo Group for Caregivers of Adults.

The DSALA served an additional 114 families with a loved one with DS in Los Angeles County this year.

Ages	2009	2010	2011
0-2	200	236	301
3-5	228	233	331
6-11	299	312	432
12-21	543	572	740
22 +	393	424	566
Total	1,663	1,777	2,370

Family Support Network

We created the Family Support Network (FSN) to bring the ideas and skills of those involved to the vast geography of Los Angeles through grassroots initiatives and connections.

This year we launched a pilot project to develop training and reporting procedures for future groups and to foster growth through grants and funding. Our pilot partners are parent support groups from Whittier, Los Angeles (Spanish Language) and the San Fernando Valley.

The FSN is an active network of community-based groups, each sharing a commitment to:

- Strengthen the Down syndrome community, locally and countywide
- Connect families with individuals with DS in their local communities
- Actively invite and welcome new community members
- Provide information for the betterment of individuals with DS
- Maintain on-going support/connection of participating community members
- Support family values of mutual respect, caring, inclusion and togetherness
- Represent DSALA's mission and activities in their local communities
- Facilitate connection of local families to DSALA
- Provide feedback to DSALA regarding local community needs and interests

“The DSALA was my first call.”



Community Groups supported by DSALA

We collaborate with other organizations in the Los Angeles area regarding common concerns about the developmental disability community. In 1990, we were proud to become one of the first affiliates of the NDSS.

Down Syndrome Affiliates in Action (DSAIA)
National Down Syndrome Society (NDSS)
National Down Syndrome Congress (NDSC)

Advisory Partnerships

- NDSC Partnership Alliance
- NDSS Advisory Committee
- Media collaboration with national organizations
- NDSC Annual Convention LEAD Seminar, San Antonio

Spanish Language

Sandra Baker leads our Spanish Language Program.

DSALA supports three Spanish-speaking parent groups: Amor y Fortaleza in Los Angeles and in the San Fernando Valley, and Cultivar y Crecer. Our eWire newsletter, new baby materials, and the DVD "The First 18 Months" is now available for Spanish speaking families.

Communication Reach

- eWire weekly electronic newsletter reaches 2,213
- Individual email announcements to 3,855
- 21 Days of T21 to 238
- Yahoo Groups for parents, teens and caregivers reaches 200
- FaceBook Page reaches 534

Conferences

- Los Angeles Mission College (students)
- Tracy Infant Center (in-service to staff)
- So. L.A. Regional Center (parents English & Spanish)
- Los Angeles Pierce College (students)
- Los Angeles Valley College (students)
- L.A. Unified at Whitney High (parents)
- Bright Star Therapies (in-service to staff)
- Family Resource Center Santa Clarita (parents)
- Carolyn Kordich Resource Center (parents)
- Miller Hospital (parents Spanish)

outreach



New Family Events

- Fall BBQ was enjoyed by 129 individuals
- Family Reunion gathered 42 individuals
- 150 new families joined the DSALA; 87 English, 63 Spanish

Physician Education and Outreach

Known as a resource with hospitals and medical professionals, the DSALA provided education and support to the following:

- Kaiser Permanente, assisted with new protocol being tested at Baldwin Park facility in pediatrics and general medicine
- Miller Children's Hospital
- UCLA: biomarkers for Alzheimer's in DS
- UCI: biomarker for Alzheimer's in DS
- UCI: Self Image in DS
- CSUN: Wii Fitness and DS

Physician education and support continue to be a top priority for our organization.

New & Expectant Parent Outreach

Hospitals call us when they come in contact with a new or expectant parent. Since 2004 we have circulated over 700 new baby kits. Last year we distributed 113; 64 in English, 49 in Spanish. We also delivered:

- 15 Outreach Kits to Professionals
- 39 Outreach Kits to Clinics
- 62 Outreach Kits to Hospitals

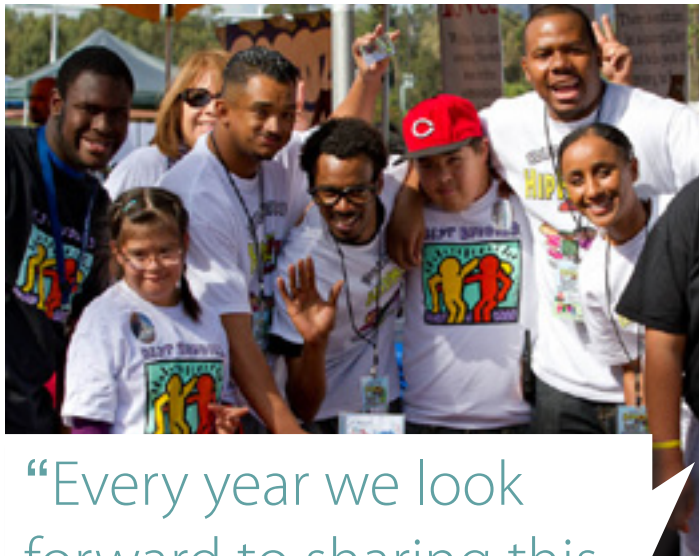
communication



Advocacy

In 2011 DSALA worked with other national organizations to maintain the positive appearance of Down syndrome in media, social networking, and the general public.





“Every year we look forward to sharing this beautiful day with our family and community.”

fundraisers

DSALA Buddy Walk

We held our 17th Annual Buddy Walk on Sunday, November 13, 2010 at Santa Anita Park. The event featured emcees Mark Wallengren and Kristin Cruz of KOST's "Morning Show."

In 2004, our event had an attendance of 900, this year, over 1,800 people shared the day and over 93 teams participated. We raised over \$123,000.

Our sub-group in Santa Barbara celebrated with their Buddy Walk and raised over \$32,000.

Buddy Walk attendance

2004	2005	2006	2007	2008	2009	2010	2011*
900	1,200	1,500	1,600	1,700	1,860	1,750	1800

*NEXT YEAR'S ANNUAL REPORT



SunDown Spring Benefit & Awards

The SunDown Spring Benefit and Awards was held on March 5, 2011 at the Lakeside Country Club. A reception and silent auction raised \$54,000.

Voices Awards were presented to individuals with Down syndrome who share their independent voice in the community.

Guillermo Loaiza for Employment
Jason Martinez for Athletics
Stephanie Tapu for Visual Arts
Mindy Zazanis for Employment

Our **Vision Awards** honor people who support individuals with Down syndrome and share their voice in the community.
JONS Marketplace for Employment
Tierra Del Sol for Education and Employment



TwentyWonder

On July 9th a sold-out crowd of 1450 guests experienced the joy, laughter and awe of TwentyWonder, "A Carnival of the Mind", at The Doll Factory in Los Angeles. Black Rebel Motorcycle Club, Exene Cervenka, and the Los Angeles Derby Dolls roller derby all-stars were among the performers.

Visitors to this epic event experienced the magic that happens when people and ideas from different cultures and disciplines come together for a truly great cause. Together, in one night, we raised over \$170,000 for DSALA, exceeding our wildest expectations.

DSALA Sports + Fitness

Sports

- Basketball funded from LA 84 foundation
- El Segundo, April & May 2011, 20 participants
- Pasadena, July & August 2011, 18 participants

Fitness

- Yoga for Teens, 6 Saturdays, 9 families
- Yoga for Babies, Monday for 6 weeks, 4 families



programs

Art Beats

Art Beats is a series of workshops where people with Down syndrome of varying ages gather in various locations throughout the greater Los Angeles area to participate in the experience of art and live music.

- reached 47 individuals the first year

DSALA Referrals

DSALA acts as a resource center for referrals provided to:

- In Home Support Services
- Individual Educational Plans (IEPs) for ages 3 to 22
- Individual Program Plan (IPPs) for ages 3 and over)
- Individual Family Service Plan, Regional Center (IFSP) for infants to 2 years old)
- Medical, Social Security, Legal, Conservatorship, Trusts, Behavior, Medical, Enrichment Programs, Area Board 10, California Developmental Disability Services, Disability Rights CA, Regional Centers
- Information provided for student projects at the Middle School, High School, Community College and University level

DSALA Actors

DSALA provides a casting liaison service for the entertainment industry when they look for talent with Down syndrome. We provide the film and television industry with People First Language and information to assist them in accurately and appropriately portraying people with Down syndrome. The service is funded by donations and run by a committee of devoted volunteers.

Employment

- Procter and Gamble commercial, 28 submitted / 3 hired
- E Entertainment, 10 photos submitted
- Chapman College, 6 submitted / 1 hired
- DSRTF I'm One of Them, 19 submissions
- DSRTF PSA, 20 submitted / 6 hired
- WalMart, 7 submitted / 1 hired
- Private Practice, 13 submitted / 1 hired
- American Horror Story, 14 submitted / 2 hired
- A Smile as Big as the Moon, 5 submitted / 1 hired
- Toys R Us ad, 17 submitted / 4 hired
- Untitled Koping Project , 4 submitted / 2 hired

Saturday Seminars

- Down Syndrome Health and Aging, 22 attended
- Potty Training, 31 attended
- Plan to Achieve Self Support, 18 attended
- Conservatorships, 17 attended
- Respect and Discipline, 17 attended
- Bohemia Management, 35 attended
- Dual Diagnosis, 30 attended

Other Activities

- Tennis Camp, 120 participants
- Teen Bowling, 12 participants
- Mom's Cruise, 47 participants
- Kings Skills Day and Game Day, 48 participants
- Cookies with Santa, 42 participants
- Push America, 2 participants
- Darnell Bing Bowling Tournament, 20 participants
- Fishing on the Betty-O, 5 participants
- CA Budget Cut Rally in Van Nuys
- DSALA Open House, 32 participants

Volunteers

We are fortunate to depend on over 50 volunteers who assist the DSALA year-round, and more than 250 who help with special events. We appreciate their time and dedication: it is priceless.



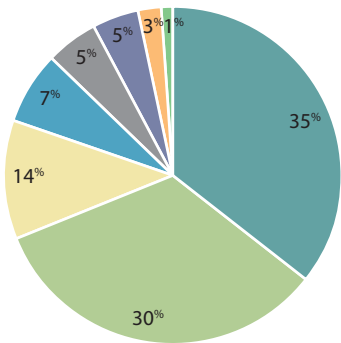
“I’m proud to work with an organization that has such positive impact.”

“I appreciate the opportunity to make a difference.”

Finances

YTD 09/30/11

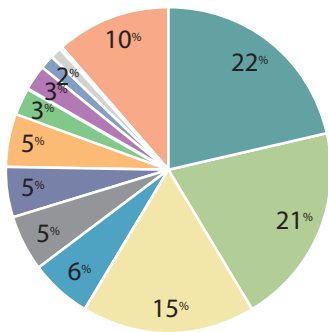
Support and Revenue	
TwentyWonder	\$171,118
Buddy Walk	159,377
Spring Event	54,174
Contributions	33,039
Grants	25,500
Program Revenue	21,598
Sports Program	11,929
Annual Appeal	4,195
Total	\$477,930



Support & Revenue

- TwentyWonder 35%
- Buddy Walk 30%
- Spring Event 14%
- Contributions 7%
- Grants 5%
- Program Revenue 5%
- Sports Program 3%
- Annual Appeal 1%

Expenses by Program	
Buddy Walk	\$103,842
Counseling	94,915
TwentyWonder	83,125
Services to Affiliates	29,153
Family Support Network	25,788
Spring Event	25,482
Sports Program	24,610
Communications	13,063
Bike Camp	12,433
New Parent Services	6,641
Annual Appeal	5,085
DSALA Actors	1,311
Change in Net Assets	54,482
Total	\$477,930



Expenses by Program

- Buddy Walk 23%
- Counseling 21%
- TwentyWonder 15%
- Services to Affiliates 6%
- Family Support Network 5%
- Spring Event 5%
- Sports Program 5%
- Communications 3%
- Bike Camp 3%
- New Parent Services 2%
- Annual Appeal 2%
- DSALA Actors <1%
- Change in Net Assets 10%

impact

In Appreciation

Thousands of generous donors provided financial and in-kind support to DSALA during the year. No donation is too small. Gifts from individuals listed here make it possible for us to provide critical services for children and adults with Down syndrome. Please consider adding your name to our growing family.

\$10,000 and above

Simon, Sam
STILA Cosmetics
L.A. Derby Dolls
The Sacchi Foundation
Linda Toibb
Von Der Ahe Foundation
Warner Bros. Entertainment, Inc.

\$5,000 to \$9,999

Vanguard Charitable
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Dharma Grace Foundation
ME ME Productions, Inc.
Mentor
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\$1,000 to \$4,999

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IPC The Hospitalist Company
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Carol & Jerry Muchin
Rudi Schulte Family Foundation

\$500 to \$999

Edison International
Tierra Del Sol Foundation
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Richard & Shari Foos
N Scott Vincent
Mark D Wallengren
Walmart Corporate Office

\$200 to \$499

AT&T United Way Campaign
Riteway Charity Services
Me So Hungry
Jose O'Malley's
Marcia & Kacy Rozelle
Glen & Lynne Shulim
Briard Restaurant Group
Kroeger
Jan Breidenbach
Marivi Garcia
Micahel Golden
Hannah Keren
Ricardo Munoz
Theresa & Jose Quevedo
Georgia & Hugh Schall
Gary Stewart
Sharon Trocki-Miller
Christopher Van Atta

In-Kind Donors

Stila Cosmetics
Kitty Fight Productions
Brad Oldham International, Inc
Brown-Forman
GV Creative
Constellation Wines
Full of Life Market



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Von der Ahe Foundation | GV Creative | Candice Albach, cover photography

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