

The Optimist

DSAOC

Down Syndrome Association of Orange County



“Dancing with the Stars”

Reflections from the 4th Annual Red Carpet Ball

Pictured to the left: Kevin VanMatre & Alex Perez at the Red Carpet Ball on February 29th, 2008, at the Anaheim Marriott Suites. Continued on page 4

Volunteer Spotlight

Thank You, Katy Dominguez!

Katy Dominguez came to us in early December to propose an idea she had for an activity for teens with Down syndrome. She wanted to volunteer her time here as part of her Girl Scout Gold Award Project (equivalent to the Eagle Scout for boys). Katy, who is a high school senior at Huntington Beach High School's Academy for the Performing Arts, wanted to teach a 5 week dance series for teens with Down syndrome ages 12-17.

The class, entitled The Dance Connection, started in mid February with a wait list that was almost double the class size! Katy, who is also a sibling of an adult with Down syndrome, never thought that the class would get the response it did.

During the 5 weekly class sessions the teens learned a variety of dances that Katy choreographed herself. The sessions concluded with a final performance for family and friends. Katy will teach another series of The Dance Connection in late April.



DSAOC Dance Connection

Left to Right: Tara, Mason, Katy (volunteer instructor), Shanel, Carter, Kevin & Alex.

In This Issue... ...and more!

- President's Message
- Spring Into the Spirit of Giving...
- Feature Article: (English & Spanish)
Meeting the Unique Concerns of Brothers & Sisters of People with Special Needs.
- Golf Tournament &
Health Conference reminders
- Reflections from DSAOC activities

Orange County Bike Camp 2008!

As announced in the April Fridge Post, we're delighted to bring you the first ever Southern California bike camp for people with disabilities, July 14th-18th, in partnership with UCP-OC.

For details and an application, visit our website at www.dsaoc.org. Your application must be post-marked or fax date stamped by April 11th.

We hope this will be the first of many camps to come!



From the President of the Board...



As we move forward in 2008, I would like to introduce myself as your new President of the DSAOC Board of Directors. I assume this position at what portends to be a great moment in the thirty year history of DSAOC. Building on the great foundation built by our previous boards, board presidents, executive director, volunteers, and most of all our community, our Center is now alive with an ever growing diversity of programs and a skilled, caring and dedicated staff.

We now have an opportunity to transition into the next phase of our presence and service. This transition will begin with a strategic planning effort aimed at setting the course of DSAOC for the next five years and beyond. Without taking a step back, we embark on goals of expanding our service to include all age groups of our citizens with Down syndrome, becoming ever more the place to go for information on best practices in health care and education, and expanding our sense of community to embrace everyone affected by Down syndrome.

We also have the opportunity, and I believe a duty, to change public perception, change public policy, and to dramatically change the data on Down syndrome – in essence, to put the human faces on Down syndrome for everyone else that we already know and see. We will do this in part in concert with our two national organizations, but we will also seek to lead where we can – after all, we are one of the most successful organizations in the nation, and sometimes change must come from the grass roots. You will hear more about me and mine, but for now, I look forward to serving you and helping DSAOC in service to our community, as we help our citizens with Down syndrome be free to be who they really are. On that journey, I hope we can let more of the world know the secret we all share – that whatever we do for our loved ones with Down syndrome, it is just a small payment of gratitude for that larger measure they have given to us.

I encourage you to write me in care of DSAOC with any ideas or concerns you might have.

With very best wishes,

Sincerely,

A handwritten signature in black ink, appearing to read "Gerard Jensen". The signature is stylized and cursive.

Gerard Jensen
President

DSAOC WELCOMES THREE NEW BOARD MEMBERS!

Janette Mattson
Brian Sinclair
David Unter

We'll be getting you better acquainted with our Board
in future issues of the Optimist



Statement of Policy and Disclaimer:

The Optimist is the periodic newsletter of DSAOC, serving Orange County, California. DSAOC is affiliated with two National Down Syndrome organizations, NDSC and NDSS. *The Optimist* reports items of interest related to Down syndrome, so that the reader may make informed decisions concerning Down syndrome related issues. Any opinions, findings and conclusions, or recommendations expressed in *The Optimist* are those of the individual authors and do not necessarily reflect the views of the officers, Board of Directors, the DSAOC organization or its membership. All medical related issues should be thoroughly discussed with your child's doctor before being implemented. DSAOC does not endorse the writings of any individual, professional or organization.

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Spring into the Spirit of Giving!



“We make a living by what we get, but we make a life by what we give.” - Winston Churchill

Did you know that DSAOC's programs, services, resources, medical & professional outreach efforts, conferences and seminars etc. are all funded through grants, sponsorships and gifts from generous donors like you?

As a 501 (c) 3 not-for-profit organization, DSAOC owes its sustainability to all who believe in the mission and the value of people with Down syndrome and have given monetary and in-kind gifts to the organization to show their support.

You can continue to help the organization thrive with your generous gifts!

Here are some reminders on how you can support DSAOC:

- ***Monthly Donations*** - A monthly tax-deductible donation can be forwarded to DSAOC directly from your Visa, Mastercard or American Express, no stamp required! You can donate as little as \$10 per month and set the date you want the donation processed. You can also change the donation amount or opt out at any time, simply by contacting the DSAOC Center. Receipts will be mailed to you. It's that easy! Contact the DSAOC Center today!

- ***Gifts through your employer*** - Does your employer have a 'Gift Match' program or 'Employee Payroll Contribution' program (such as United Way)? Designate DSAOC as the non-profit recipient! Your employer may be able to match your gift. You can also donate through various types of payroll contribution programs allowing your tax-deductible gift to be automatically submitted to DSAOC.

- ***Gifts of Appreciated Stock and Bequests in your Will*** - DSAOC now has accounts set up to handle generous donations like this. We can put you in contact with someone or you can consult with your own financial planner.

Contact the DSAOC Center for more information. Thank you in advance for your support!

Valero Refinery, Wilmington, CA, Presents the Down Syndrome Association of Orange County with a check for \$10,000!

For the 3rd year in a row, the Valero Refinery in Wilmington, CA, has donated \$10,000 to DSAOC to support our programs.

A big THANKS to Valero employee, Matt Wilkins, for his nominations requesting that this annual donation be made to DSAOC.

Matt Wilkins is one of our DSAOC Dads and a member of our Board of Directors. Each year he places a nomination for DSAOC to receive this gift from Valero Refining through Valero's Texas Open Golf Classic; an event benefitting children.

Mark Rodriguez, Design Engineering Supervisor at the Valero Wilmington Refinery, presented the check to DSAOC in February this year. Mark not only supports DSAOC's mission by supporting the nomination, he is also a hard working volunteer at our annual Buddy Walk. He and Matt bring other wonderful volunteers from Valero that not only help on the day of the Buddy Walk, they also assist with the pre-event set-up the day before!

Thank you Matt, Mark and Valero for all of your support!!



*Mark Rodriguez (Supervisor - Valero Wilmington Refinery),
with several of our Learning Program participants.
February 2008*

*Contact the Center and let us know your unique plans to raise funds for DSAOC. Are you having a Car Wash, Yard Sale or recycling?
Send us pictures and we may be able to publish your story in the next Optimist!*

★ “Dancing with the Stars” ★

★ DSAOC’s 4th Annual ★ ★ Red Carpet Ball ★

★ February 29th, 2008 ★

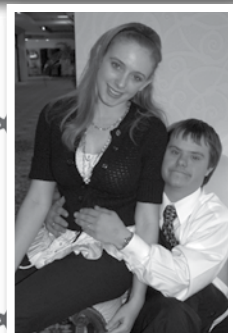
★ Friday, February 29th was a night to remember!

With a theme of “Dancing with the Stars” and decorations in black and silver, the Crystal Ballroom of the Anaheim Marriott Suites was transformed for our annual formal event.

72 teens and adults with Down syndrome and 11 friends with other disabilities dined, danced, socialized with friends and enjoyed an environment that promoted and respected their independence. The festive music, provided by our very own DJ Will Power, allowed the guests to dance the night away until 11pm. They also posed for formal photographs and took their pictures home in photo-wallets that doubled as autograph books.

The ball’s self-advocate planning committee worked with DSAOC staff to create an exciting, fun evening. Sydney Taylor came up with the theme, and when asked, “Who are the stars?” she replied: “We are!”

A big “Thanks” to our fabulous crew of volunteers who helped to make the evening memorable!



Program Director Pick

What About Siblings?

by Kristi Golden, Program Director, DSAOC



Dear Readers,

I have two sons. They both have and don't have many things, but I'll focus on the issue at hand. Ben, who is 14, has Down syndrome, and Alex, who is 10, doesn't have Down syndrome. Both boys are uniquely wonderful in their own right.

When Ben was born, our developmental pediatrician said to me, "First things first: Enjoy your baby. Don't spend all your time focused on the fact that Ben has Down syndrome. Remember to take time to be a normal family." Good advice. It helped me keep in check. I made an effort to keep things in perspective and not let all of Ben's needs dominate our family's schedule and priorities (that tended to happen, though. I admit). But the pediatrician's advice became even more important when our second child was born.

In the early years I actually felt pretty normal, and Ben and Alex were the best of friends! Along the way, I started noticing that Alex had some needs that were related to his brother. I started seeing a bigger picture and began learning that siblings of children with special needs have special needs themselves.

I would like to share a few ideas and resources I've gleaned from books, conversations and the web:

1. When parents tune in to each child's individual needs, each child is affirmed and the difficulties may diminish. You can help your kids better understand what having a sibling with special needs means to your family, and you can also help your kids figure out constructive and appropriate ways to express their feelings and get their needs met.
2. Always talk openly about Down syndrome. There is nothing to hide and it's a fact of your family's life.
3. Learn the basics of sibling rivalry. There are many books out on this topic, available at your public library. Sibling Rivalry is normal and healthy.
4. Check out the *Sibling Support Project* by visiting their website at www.siblingsupport.org. This is a national project for brothers and sisters of people with special health and developmental needs. The Project's main goal is to promote

peer support and education programs for brothers and sisters of people with special needs. They create books (we have some in our resource library) and newsletters to raise awareness, conduct workshops, and sponsor listservs. In fact, they run a listserv just for kids, called SibKids. Check out our Feature Article on page 6, authored by the director of this project, Don Meyers.

5. If you have siblings in the age range 8 to 12, I highly recommend the monthly sibling workshop called **Super Sibs Klub**. This is a free, 2½ hour program on the third Saturday of each month. This program is a collaborative between UCI Medical Center and CHOC. It is facilitated by a Child Life Specialist, a Registered Nurse and community volunteers, some of whom are siblings of individuals with special needs, too. (More info below)

Our family is constantly growing, gaining a broader understanding of our relationships, the roles we play, and the support we give to one another. For Alex, Super Sibs Klub provides a place to open up, to be himself, where all the kids have one thing in common: A sibling with special needs. I pick him up after the workshop. He always brings a project home. Last time it was an anger management kit. Another time he made a journal.



"What do you like about Super Sibs, Alex?" I ask. "We play hard, and have fun. And we help each other solve problems. And we understand."

Enough Said.

More About Super Sibs Klub

Their philosophy:

All children are special in their own way. Super Sibs Klub focuses on the strengths of children who have brothers/sisters with special needs. Participants engage in fun-filled activities to develop appropriate coping strategies to use with daily challenges.



Siblings, Alex and Ben Golden - playing one of many games they enjoy together.

The Goals for Super Sibs Klub:

Provide a safe, supportive group environment that welcomes open communication and education amongst peers. By acknowledging the joys and concerns about being a sibling, children develop coping skills and strategies that transfer to everyday life.

Super Sibs Klub
UCI Medical Center
Neuropsychiatry Center, Room 101
101 The City Drive, Orange, CA 92868
The Third Saturday of the Month, 9:30 to 12 noon.
Call Yvonne at (714) 532-8778 to Register

Meeting the Unique Concerns of Brothers and Sisters of People with Special Needs

Donald Meyer, Director
The Sibling Support Project of The Kindering Center, Seattle, Washington

In the United States, over five million children have disabilities or special health concerns. Most have brothers and sisters. Throughout their lives, these brothers and sisters will share many--if not most--of the same concerns that parents of children with special needs experience, as well as issues that are uniquely theirs. These concerns are well known to their parents and have been documented in the research and clinical literature. Among the concerns mentioned by authors, parents, and siblings themselves include:

- a life-long and ever-changing need for information about the disability or illness (Lobato, 1990; Schorr-Ribera, 1992; Powell & Gallagher, 1993).
- feelings of isolation when siblings are excluded from information available to other family members (Bendor, 1990), ignored by service providers (Doherty 1992), or denied access to peers who share their often ambivalent feelings about their siblings (Meyer & Vadasy, 1994);
- feelings of guilt about having caused the illness or disability, or being spared having the condition (Koch-Hattem, 1986),
- feelings of resentment when the child with special needs becomes the focus of the family's attention or when the child with special needs is indulged, overprotected, or permitted to engage in behaviors unacceptable by other family members (Poddeanu-Czehotsky, 1975; Bendor, 1990);
- a perceived pressure to achieve in academics, sports, or behavior (Coleman, 1990);
- increased caregiving demands, especially for older sisters (Seligman, 1979); and
- concerns about their role in their sibling's future (Fish & Fitzgerald, 1980; Powell & Gallagher, 1993).

Increasingly, opportunities experienced by these brothers and sisters are also being acknowledged (Meyer & Vadasy, 1994; Powell & Gallagher, 1993; Turnbull & Turnbull, 1993). A short list of opportunities observed by parents and brothers and sisters could include:

- the insights a sibling will have on the human condition as a result of growing up with a brother or sister with special needs: "She taught me how to love without reservation; without expectation of returned love. She taught me that everyone has strengths and weaknesses. Martha is no exception. She taught me that human value is not measured with IQ tests." (Westra, 1992, p.4)
- the maturity many brothers or sisters develop as a result of successfully coping with a sibling's special needs: "I have a different outlook on life than many other people my age. I understand that you can't take anything for granted. And you have to be able to look at the positives...With Jennifer, there are negatives, but there's so much more that is good." (Andrea, age 19, in Binkard et al., 1987, p. 19);

- the pride brothers and sisters report in their sibling's abilities: "Jennifer has probably achieved more than I have. She's been through so much. She couldn't even talk when she started school; now she can, and she can understand others. She's really fulfilling her potential. I'm not sure the rest of us are." (Cassie, age 18, in Binkard et al., 1987, p. 17)

- the loyalty brothers and sisters display toward their siblings and families: "I'm used to being kind to my brother and sister, so I'm kind to everybody else. But, if someone starts a fight, I will fight. I won't put up with anyone teasing Wade or Jolene." (Morrow, 1992, p.4)

- and the appreciation many brothers and sisters have for their good health and own families. "Living with Melissa's handicaps makes me so much more cognizant of my own blessings. She provides a constant reminder of what life could have been like for me if I had been my parents' oldest daughter. This encourages me to take advantage of my mental capacities and to take care of my healthy body." (Watson, 1991 p. 108)

Acknowledging siblings' many unique opportunities is not to view their experience from Pollyanna's perspective--many of these benefits are hard-earned. In short, siblings' experiences closely parallel their parents' experiences.

Within the family, siblings will likely spend more time with the child with special needs than any other person, with the exception of the child's mother. And, because the sibling relationship is generally the longest-lasting relationship in the family, brothers and sisters are likely to experience these concerns for a long period of time. Sibling issues are, consequently, lifespan issues: preschool age siblings will grapple with issues not faced by their peers in the community; so will siblings who are senior citizens. Yet, many brothers and sisters grow up without resources--such as access to support programs and sources of information--that would help them in their roles, and that many parents may take for granted.

Below are suggestions for parents and service providers to minimize siblings' concerns and maximize their opportunities:

1. *Provide brothers and sisters with age-appropriate information.* Most brothers and sisters have a life-long, and ever-changing need for information. Parents and service providers have an obligation to proactively provide siblings with helpful information. Agencies representing specific disabilities and illnesses should be challenged to prepare materials specifically for young readers.

2. *Provide siblings with opportunities to meet other siblings of children with special needs.* For most parents, the thought of "going it alone," without the benefit of knowing another parent in a similar situation is unthinkable. Yet, this happens routinely to brothers and sisters. Sibshops and similar efforts offer siblings the same common-sense support that parents value. They let brothers and sisters know that they are not alone with their unique joys and concerns.

3. *Encourage good communication with typically developing children.* While good communication between parent and child is important, it is especially important in families where there is child with special needs. An evening course in active listening can help improve communication among all family members. Also, books, such as *How to Talk So Kids Will Listen and Listen So Kids Will Talk* and *Siblings Without Rivalry* (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.

4. *Encourage parents to set aside special time to spend with the typically developing children.* Children need to know from their parents' deeds and words that their parents care about them as individuals. When parents carve time out of a busy schedule to grab a bite at a local burger joint or window shop at the mall with the typically developing child, it conveys a message that parents "are there" for them as well.

5. *Encourage parents and service providers to learn more about siblings' experiences.* Sibling panels, books, newsletters and videos are all excellent means of learning more about sibling issues. A bibliography is available from the Sibling Support Project.

6. *Encourage parents to reassure their typically developing children by planning for the future of the child with special needs.* Early in life, brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Parents should be encouraged to plan for the future and share these plans with their children. When brothers and sisters are "brought into the loop" and given the message that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation.

adapted from Sibshops: Workshops for Brothers and Sisters of Children with Special Needs, 1994, by Donald J. Meyer and Patricia F. Vadasy (Baltimore: Paul H. Brookes). All right reserved.



The Sibling Support Project of
The Kindering Center
6512 23rd Ave NW #213
Seattle, WA 98117
phone: 206-297-6368
donmeyer@siblingsupport.org
www.siblingsupport.org



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Reminder

2008 DSAOC Charity Golf Tournament



Register EARLY!
On or before
May 2nd and pay
only \$220!
After May 2nd fee is \$240

Monday, June 16th, 2008
Los Coyotes Country Club, Buena Park
Registration and Driving Range open at 10 am
Putting Contest at 10:45 am - Shotgun Start at 11:30 am
Terrace activities (cash bar, silent auction) opens at 4:30pm
Dinner & Awards Banquet begins at 5:30pm

**Early Registraton
Discount!**
**\$20 off your
registration!**



Golfer Registration Includes:

- A round of golf at the Country Club
- A golf cart for your team
- A golfer goody bag filled with exciting items
- Pastries, coffee, water during registration
- Automatic entry into the Tournament Player's Package
- Golf Polo Shirt
- 3 Opportunity Drawing Tickets
- Wahoo's Lunch
- Beverages on the course (beverage carts & free beer at some turns)
- After the tournament: Lite hors 'deurves on the terrace, Cash Bar, Silent Auction
- Dinner & Awards Banquet



Player's Package includes a \$10,000 PUTT-OFF!

All 4 Closest to the Pin Winners
will be entered into the PUTT-OFF for a
chance to win \$10,000!



The Annual Golf Tournament proceeds go toward programs, services & seminars offered to the community in response to various needs. Contact DSAOC today to Register for this fun-filled, worthwhile event! (714) 540-5794

Stories From the Hearts of our Families...

Volunteering Brings out Nancy's Passion...

Contributed by Nancy's mom, MaryAnn Brock

My daughter, Nancy Elizabeth Brock, has been involved in many community activities over her twenty years of life. At Currie Middle School and at Tustin High School, Nancy was on the Honor Roll and was Student of the Month. She has proudly performed as a Tustin Pop Warner Cheerleader since 2002. She competes in tennis, volleyball, and floor hockey in Special Olympics. She plays AYSO Soccer. At the Boys and Girls Club of Tustin, Nancy was the 2006 Air Hockey champ! Perhaps her most meaningful community experience has been her involvement in Girl Scouts. Through support from the typical peers in her troop, and the amazing Scouting leadership, scouting became an integral aspect of Nancy's school years. During her Girl Scout career, Nancy earned all the honors any girl can earn.

The pinnacle award in Girl Scouting is called the Girl Scout Gold Award. The Gold Award project is the culmination of all the work a girl puts into "going for the Gold." It is something that a girl can be passionate about—in thought, deed, and action. The project should be something that fulfills a need within a girl's community, creates change, and hopefully, becomes ongoing. Nancy worked toward the Gold Award, investing over 100 hours in the required areas. The last step was the Final Project. But in 2007 we were at a crossroads: Nancy had not identified a Final Project, and she was with 6 months away from "aging out" of scouting.

Nancy needed to find a project she was passionate about. Born with Trisomy 21, Nancy does not communicate in more than one- to-three word phrases, even after years of speech therapy. Despite her communication skills, she had 20 great years of life experience. I knew that there must be a project inside her, but Nancy could not verbalize her "passion." I was at a loss as to how to help her bring it out.

Then it happened: At the DSAOC summer picnic in 2007, Nancy and I met the Volunteer Clowns of Orange County. They have been an "institution" at DSAOC events for years! I asked them if she could be a "practice" clown that day, just for fun. The clowns painted her face; she shadowed another clown doing "meet and greet" (offer "happy face stickers" to guests). When I thought Nancy was getting too silly, her "mentor" clown told me, "She's a clown. She's fine". Nancy was so happy. When she was finished with her "job", I asked her if she wanted to be a clown, she quietly said "yes". I told her that clowns have a name. "What is your clown name?" I asked. She thought about it for a minute. I saw those wheels in her head spinning, and then she said "BBBBB". We both laughed out loud. "Hello, BBBBB the clown!" Nancy found her passion!

The July 1st deadline for the last 2007 Gold Award project submission was just weeks away. The Troop advisor needed to witness Nancy's passionate decision. She asked Nancy "Are you a clown?" Nancy said "Yes". The advisor asked "what is your clown name?" Nancy said "BBBBB". The advisor saw the passion on Nancy's face. Now the final piece was in place.

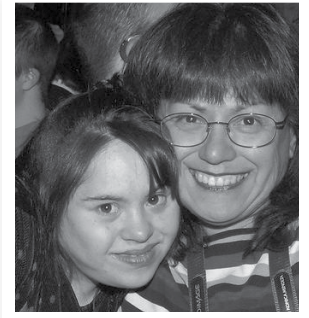
Senior Girl Scout Troop 1015 Advisors provided adaptive guidance for the project submission entitled, "Clown Around, Making the World A Happy Place". This was a two part effort: 1) Nancy becomes a clown with the support of the Volunteer Clowns of Orange County, and 2) Nancy organizes and participates in a 'Be A Clown Day' at the Boys and Girls Club of Tustin.

Nancy and I attended a monthly Volunteer Clowns meeting. She signed up to be a clown for 13 events or gigs. Throughout September and October, the weather was a challenge – and neither the Santa Ana winds, nor rain, nor fog, nor the fire threat kept us from attending the gigs. We were scheduled to attend the DSAOC Halloween Party – but it was cancelled due to the fire. But the "Be A Clown Day" on Oct 26th, at the Boys and Girls club was a wild success providing humor to over 200 kids. The Club plans to make this an annual event. BBBBB has become a minor celebrity. Nancy invested over 96 hours to meet the Gold Award 4Bs Challenge and complete her project. On November 6, 2007, Nancy Brock completed Girl Scouting's highest recognition, The Gold Award.

On December 1st, BBBBB the Clown, came full circle: Nancy discovered her clown passion at the DSAOC picnic in June. Now, as a full fledged clown, she volunteered at DSAOC's Breakfast with Santa event on Saturday, December 1st.

Nancy Brock, as "BBBBB the Clown", enhances the Girl Scout community service image by bringing joy to the community and demonstrating that Girl Scouts can create positive self images for all girls, including those with special needs. Nancy enjoys increased self esteem from giving to a community that has been supportive of her and her audience witnesses the validation that we all have value.

Behind the grease paint and under the wig, is a young woman coming into her own.



DSAOC Center Update

“More Alike Than Different”

More Alike Than Different – that’s the theme of the new public awareness campaign being produced by the National Down Syndrome Congress (NDSC). It’s still a work in progress, but one that you will start to see rolled out in print media and television over the coming months. We look forward to that roll-out here in Orange County.

The goal is to replace the myths and misconceptions about people with Down syndrome with evidence that they are more alike – they share many of the same hopes and dreams, likes and dislikes; they love their families, value their friends, root for the home team, and cope with the challenges of daily living – more alike than different.

The campaign ads do not highlight any grand slams, gold medals, or extraordinary achievements; rather they show a series of young adults with Down syndrome talking about sports, jobs, relationships, and the things that compose ordinary life. More alike than different – their stories clearly demonstrate lives to be valued.



Lanny L. Hardy
Executive Director, DSAOC

While NDSC is to be commended for getting this project off the ground, there will be two critical keys to its success. First, it must be a long term strategy. Attitudes can be difficult to change and it will not happen without a consistent message that is reinforced over time. And second, it will take a commitment at the local level to see that these stories are seen and heard in each of our communities.

With that in mind, the DSAOC Board of Directors has voted to support the program financially and perhaps more importantly with the commitment to be a campaign partner by integrating its message into our own plans for improved public awareness here in Orange County. We’ll be sure to keep you updated on our progress. In the meantime, for more information about the More Alike Than Different campaign, or to see the first round of campaign ads visit: www.ndsccenter.org.

“Educator of the Year” **Nomination Information** **for 2008**

The **2008 DSAOC Educator of the Year Award** is back again this year so we can continue to affirm and celebrate those in education whose outstanding efforts and innovations have helped a student to grow and learn.

Please help us bring quality educators to the forefront, affirm their efforts, and share what is being done well.

If a teacher, therapist, aide or administrator has made a difference for your child, consider nominating them for this award.

The 2008 DSAOC Educator of the Year will be selected in early June and will be presented with a plaque and recognized at a celebration at his or her school site prior to the end of this school year. All nominees will be recognized at our Fall Education Workshop where we will honor their exceptional contributions to educating children with Down syndrome.

To nominate an educator for this award:

Begin putting your nomination letter together and then [watch for the Nomination form in your May Fridge Post.](#)

Not receiving the Fridge Post? Call us for a nomination form. Nominations must be received in the DSAOC Center no later than Tuesday, May 27th, 2008.

Bella's Kitchen

"Pizza Chef for a Day!"

Thank you Joe D'Angelo, Bella's Staff and Volunteers for another fun-filled day with friends and family at Bella's Kitchen!



Joe D'Angelo and his fiancée Adrianna, with the Teens & Adults that were "Pizza Chefs for the Day!"



For the second year in a row, Joe D'Angelo (owner of Bella's Kitchen) opened his restaurant on a Saturday, brought in staff and invited our Teens and Adults, along with their families, to join together for a delicious pizza dinner, and to see the 'behind the scenes' of a food business.



Joe's family of volunteers (Adrianna, Brianna & Ethan) & Staff helped to transform our Teens & Adults into "Pizza Chefs for the Day" by providing them chef hats and all the makin's for their very own personal sized pizza's!



The DSAOC Volunteer Crew that assisted with the Bella's Kitchen event. We appreciate you!!



Behind the scenes in the kitchen, this group patiently waits for their pizzas to finish cooking.

Bella's Kitchen is named after Joe's daughter who has Down syndrome. Bella's Kitchen is located at 301 The City Drive in Orange. Stop in for lunch or order take out. Bella's is open Monday-Friday.

Grupo de Apoyo Arcoiris

Para padres con hijos con síndrome de Down. Somos padres de familia como ustedes dedicados a nuestros hijos e hijas trabajando unidos para ofrecerles una vida plena de gozo, amor, aprendizaje y bienestar.

Los invita a sus reuniones mensuales que se llevaran acabo cada:

Tercer Viernes del Mes

de 10 am a 12 medio dia en el:

Dayle McIntosh Center
13272 Garden Grove Blvd.
Garden Grove, CA 92843

Para mas información llame a:
Maria Pecina (714)558-540,
Cecilia Mercado (714)533-5815,
o Alicia Sanchez (714)540-5794



Hemos agregado nueva informacion en nuestra seccion en espanol de nuestra pagina web: www.dsaoe.org

Porfavor visitenos!

Quiero animar a nuestras familias hispanas que por favor me acompanen a la reuniones del Grupo de Apoyo Arcoiris. Es muy especial cuando pasamos tiempo juntos para compartir. Los espero este mes!

Sinceramente,

Alicia Sanchez
Cordinadora Bilingue
de Programas
Down Syndrome Association
of Orange County



Calendario Trimestral

Abril

- 04/01 Karate 4:30p-5:30p (7-12 años), 5:30p-6:30p (12 años y mayor)
6:30p -7:30p (12 años y mayor) Esta clase es cada Martes esta fin de año
- 04/09 7p -9p Seminario: "Como escribir buenas metas y objetivos en su IEP"
- 04/17 7p-9p Presentación por terapeutas de ocupacional y de lenguaje
"Como reducir al mínimo batallas con nuestros hijos a la hora de comer"
- 04/18 8a -5p Conferencia de Salud para adolescentes y adultos con el síndrome de Down
- 04/19 8a -5p Conferencia de Salud para adolescentes y adultos con el síndrome de Down
- 04/23 4p -5p Clases de Baile para edades 12 a 17 años
(esta clase es cada Miercoles por 5 semanas)
- 04/25 10a-12p Grupo de Apoyo Arcoiris en el Dayle McIntosh Center
- 04/25 7p -9p Noche de actividad para jovenes con síndrome de Down
(12-17 años) Noche de Baile "Western"
- 04/28 3:30p-5:30p Actividades después de la escuela para niños edads 6- 11 años.

Mayo

- 05/15 7p -9p Seminario: "El tiempo dedicado haciendo tareas con su hijo puede ser divertido"
- 05/16 10a -12p Grupo de Apoyo Arcoiris en el Dayle McIntosh Center
- 05/26 Dia festivo "Memorial Day" (oficina cerada)

Junio

- 06/02 7p-9p Presentación por terapeuta de lenguaje
"Como hacer el lenguaje de su hijo mas facil de entender"
- 06/16 11:30a -7p Torneo de Golf
- 06/20 10a -12p Grupo de Apoyo Arcoiris en el Dayle McIntosh Center
- 06/21 11a -2:30p DSAOC Picnic Anual para la Familia

Satisfacer las Preocupaciones de los Hermanos y Hermanas de Personas con Necesidades Especiales

Donald Meyer, Director

The Sibling Support Project, Seattle, Washington

En los Estados Unidos hay mas de cinco millones de niños con discapacidades o con preocupaciones especiales de salud. Muchos de estos niños tienen hermanos y hermanas. Durante sus vidas, los hermanos y hermanas compartiran muchas de las mismas preocupaciones, experiencias y asuntos unicos a los de padres de hijos con necesidades especiales. Estas preocupaciones son muy conocidas por sus padres y han estado documentadas en investigaciones y literaturas clinicas. Entre las preocupaciones mencionadas por los autores, los padres, y hermanos incluyen los siguiente :

- Una necesidad grande por obtener informacion sobre la discapacidad o enfermedad.
- Sentimientos de aislamiento cuando los hermanos estan excluidos de la informacion a disposicion a otros miembros de familia, estan ignorados por los proveedores de servicios, o se les niega el acceso de comunicarse con compañeros quien comparten los mismos sentimientos ambivalentes acerca de sus hermanos con necesidades especiales.
- Sentimientos de culpa por haber provocado la enfermedad o la discapacidad, o el sentimiento de ser librado de tener la condicion.
- Sentimientos de resentimiento cuando el hermano con necesidades especiales es el enfoque de la atencion de la familia, o el hermano con necesidades especiales es consentido, sobre protegido o le es permitido hacer comportamientos no aceptados por otros miembros de familia.
- Una presion percibida de lograr en el mundo academico, los deportes, o de comportamiento.
- Exigir que esten mas al cuidado del hermano con necesidades especiales, especialmente exigen a las hermanas mayores.
- Preocupaciones sobre el papel que van a tomar en el futuro de su hermano con necesidades especiales.

Cada vez más, las oportunidades experimentadas por estos hermanos y hermanas tambien estan siendo reconocidos. Una breve lista de oportunidades observadas por los padres y hermanos podrian incluir lo siguiente :

- Las ideas un que hermano o hermana tendran sobre la condicion humana como resultado de crecer con un hermano con necesidades especiales. " Ella me enseno como amar sin condiciones ; sin expectativas de regresar el amor. Ella me enseno que todos tenemos fuerzas y debilidades. Martha no es una excepcion. Ella me enseno que el valor humano no es medido con una prueba de inteligencia".

- La madurez que muchos de los hermanos y hermanas han desarrollado fue por el resultado del buen éxito que tuvieron en su relacion con su hermano con necesidades especiales. "Tengo una vista de la vida diferente que otros de mi edad. Yo entiendo que no se puede dar nada por descontado. Tiene uno que ver lo positivo...con Jennifer, no hay negativos, hay mucho mas de lo que es bueno". (Andrea edad 19)

- El orgullo de los hermanos y hermanas es reportado en las habilidades de sus hermanos con necesidades especiales. "Jennifer quizas ha logrado mas que yo. Ella a pasado por mucho. Ella no podia caminar cuando empeso la escuela ; ahora ya puede y puede entender a otros. Ella esta llegando a su potencial. No estoy seguro de que el resto de nosotros llegaremos a esto".

- La fidelidad que demuestran los hermanos y hermanas hacia sus hermanos y familias : "Yo estoy acostumbrado a ser amable con mis hermanos y hermanas, por eso soy amable con todos. Pero si alguien inicia una lucha, voy a luchar. Yo no admito que alguien moleste a Wade o Jolene".

- El agradecimiento que muchos hermanos y hermanas tienen por tener su buena salud y por sus propias familias. " Viviendo con la discapacidades de Melissa me hacen reconocer mas mis bendiciones. Ella constantemente me recuerda de como podria ver sido mi vida, si yo fuera la mayor de las hijas. Esto me anima a tomar ventaja de mis capacidades mentales y de cuidar de mi cuerpo saludable".

Reconociendo las muchas oportunidades unicas de los hermanos, no es de ver sus experiencias desde la perspectiva de Pollyanna – muchos de estos beneficios son merecidos. En resumen, las experiencias de los hermanos paralelan de las experiencias de sus padres.

Dentro la familia, es probable que los hermanos pasan mas tiempo con el niño con necesidades especiales que cualquier otra persona, con la excepcion de la madre del niño. Y debido a que la relacion entre hermanos, es generalmente la relacion mas larga duracion en la familia.

Hermanos y hermanas son propensos a experimentar estas preocupaciones durante un largo periodo de tiempo. Las cuestiones de los hermanos, son en consecuencia, cuestiones de vida ; hermanos de edad preescolar lidiaran con cuestiones que no se enfrentan por sus pares en la comunidad; igual les pasa a los hermanos que ya son personas adultas de edad mayor.

Sin embargo, muchos hermanos y hermanas crecen sin recursos – tal como acceso a programas de apoyo, y fuentes de información que les ayudan en sus funciones como hermanos, y que quizás muchos padres pueden dar por descontado.

Lo siguiente son sugerencias para los padres y proveedores de servicios para minimizar las preocupaciones de los hermanos y para aprovechar al máximo sus oportunidades.

1. Proveer a los hermanos y hermanas información apropiada para ellos. Muchos de los hermanos y hermanas de niños con necesidades especiales tienen una necesidad grande por obtener información sobre la incapacidad o enfermedad. Los padres y los proveedores de servicios tienen la obligación de proveer a los hermanos de manera proactiva con información útil. Las agencias representando discapacidades o enfermedades específicas deben sentirse obligados a preparar materiales específicamente para los jóvenes lectores.

2. Proveer a los hermanos con oportunidades para conocer a otros hermanos de niños con necesidades especiales. Para la mayoría de los padres, la idea de “lo estoy haciendo solo” sin el beneficio de conocer a otro padre con la misma situación es impensable. Sin embargo, esto les pasa a los hermanos y hermanas de niños con necesidades especiales. “Taller de hermanos” y otros esfuerzos similares, ofrecen a los hermanos el mismo apoyo que los padres valoran. Dejan saber a los hermanos que no están solos en sus alegrías y sus preocupaciones únicas.

3. Animen la buena comunicación con los niños en desarrollo típico. Mientras que la buena comunicación entre

el padre y hijo es importante, es especialmente importante en familias con un niño con necesidades especiales. Tomando un curso con tema de “escuchar activamente” puede ayudar en la comunicación entre los miembros de la familia. Igual, libros como “Como hablar para que los niños escuchen y como escuchar para que los niños hablen” y “Hermanos sin rivalidad” ayudan con buenos puntos en como comunicarse con los niños.

4. Animen a los padres a que pasen tiempo especial con los niños en desarrollo típico. Los niños deben de saber por las acciones y palabras de sus padres que sus padres están interesados de ellos como individuos. Cuando los padres toman el tiempo de su horario acupado y salen a comer o salen a las tiendas para compras, esto transmite un mensaje de que los padres están “desponibles para ellos”.

5. Animen a los padres y los proveedores de servicios a que aprendan más de las experiencias de los hermanos. Libros, revistas, videos son medios excelentes para aprender más de los asuntos de hermanos. Una biografía de “Proyecto de apoyo para hermanos” es desponible.

6. Animen a los padres a que aseguren a sus hijos de desarrollo típico, que si están planeando el futuro para el hijo con necesidades especiales. Los hermanos y hermanas se preocupan desde temprano en la vida, sobre las obligaciones que tienen con su hermano con necesidades especiales. Padres deben de compartir estos planes del futuro con sus hijos. Cuando los hermanos y hermanas se les da el mensaje de que tienen la bendición de sus padres para perseguir sus sueños, su futuro con participación de sus hermanos con necesidades especiales y de saber que será una opción en lugar de una obligación.

adapted from Sibshops: Workshops for Brothers and Sisters of Children with Special Needs, 1994, by Donald J. Meyer and Patricia F. Vadasy (Baltimore: Paul H. Brookes). All right reserved.



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We Appreciate our Interns!

We are fortunate, once again, to have interns from Cal State Fullerton working with us for spring semester.



Peggy Watson is a Senior in Human Services, and will graduate this spring. She is interested in geriatrics, so our Health Conference for Adults with Down Syndrome is of particular interest to Peggy. Peggy has been instrumental in researching and updating our resource & referral binders and our New Parent Information binder. Peggy maintains a full time career as a hair stylist and is a wife, mother and grandmother. She will bring a wealth of experience into her future career in Human Services.



Dora Gutierrez is a Senior in Human Services, and will then pursue a Masters in Psychology. She would like to become a special education teacher and eventually become a school psychologist. She currently works as an instructional aid for the Garden Grove School District. At DSAOC, Dora has been working on the upgrade and expansion of our Resource Library. She has also assisted us with various program activities, including supporting the Learning Program.

Health Conference Reminder

April 18th & 19th, Presented by DSAOC

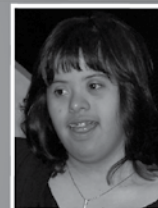
Don't miss this exciting opportunity to hear national and local experts! Call 714-540-5794 or go to www.dsaoc.org and download the conference brochure and registration form.

Is your son or daughter's doctor attending the Physician Breakfast? Be sure to send us their physician's name and address or email address. We would be happy to invite them to attend the complimentary breakfast seminar on Friday, April 18.

 **Hilton**
Orange County / Costa Mesa

Friday & Saturday
April 18th & 19th, 2008

2008 Conference on Health Issues in Adolescents & Adults with Down Syndrome



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info@dsaoc.org
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Orange County:
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North (714) 796-3700
South (714) 796-4060
West (714) 796-2900
TASK
(714) 533-8275
Comfort Connection FRC
(714) 558-5400
Special Olympics OC
(714) 564-8374
Orange County ARC
(714) 744-5301
The ARC of the U.S.
(301) 565-3842
Center for Law &
Social Policy
(202) 797-6535
National Down Syndrome Congress
www.ndscenter.org
National Down Syndrome Society
www.ndss.org
Education Research
www.downsnet.org
Inclusion Press Home Page
www.inclusion.com
Special Olympics
www.specialolympics.org
Wrightslaw
www.wrightslaw.com
Disability Solutions
www.disabilitysolutions.org
Down Syndrome Quarterly
www.denison.edu/dsq/
Down Syndrome Health Issues
www.dshealth.com
Assistive Technology
www.abledata.com
Protection & Advocacy
www.pai-ca.org
Riverbend Parent Support
www.altonweb.com/cs/downsyndrome/index.n



Down Syndrome Association of Orange County

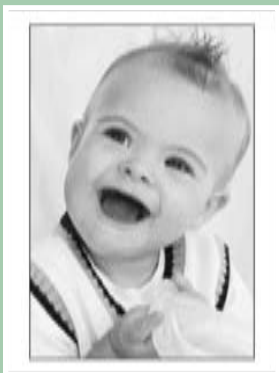
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Behavior Training Schedule for Spring/Summer 2008
 For Information or to Register, call Thelma Day at (714) 796-5223.

Dates	Times	Location	Content	Language	Instruct ors
Thur sdays, Mar 6, 13, 20, 27, Ap ril 3, 10, M ay 1	6:30 – 9:00pm	RCOC Irvine	Social Sk ills Trainin g (for parents – focu s is youth ages 5 - 11)	Eng lish	Erin Davis, M.A. (Behavioral Suppor t Partnership)
Tuesdays, April 1, 8, 15, 22, 29	6:30 – 9:00pm	RCOC Santa Ana	Basic Behavior Management (the last sessi on is toilet training)	Eng lish	Joyce Tu, Ed.D. , BCBA
Thur sdays, May 1, 8, 15, 22, 29	6:30 -9:00pm	RCOC West- minster	Basic Behavior Management (the last sessi on is toilet training)	Spanish	Ana Lorenz, Ph.D.



Office Hours:
 Monday through Friday
 9am until 5pm

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