

# What's the Buzz...



**Water Safety:** As we say goodbye to Summer and hello to Fall, our continued high temperatures will no doubt keep many families by their home pools, or the community pools, or at the beach. With the holidays coming up, there's a lot on our minds and plenty of distractions, even for the most attentive parents. Here is a link to some very important information and reminders about Pool Safety for our families: [www.ockeepkidssafe.org/pdfs/PoolSafetyPosterEng.pdf](http://www.ockeepkidssafe.org/pdfs/PoolSafetyPosterEng.pdf)

**West Nile Virus:** *Speaking of water...* remember to empty standing water from flowerpots, gutters, buckets, pool covers, pet water dishes, discarded tires, and birdbaths on a regular basis to help reduce the number of mosquitoes around your home, and use mosquito repellent. Orange County has had a record West Nile Virus season in 2014, with a total of 94 human infections reported to date. The County's previous high for a season was 79 cases in 2008. Santa Ana has had the highest number of infections of any city, but cases are now being reported throughout the county. Because mosquitoes usually pick up West Nile virus from infected birds, the shortage of water also helps increase the share of insects carrying the disease. "When we have less water, birds and mosquitoes are seeking out the same water sources, and therefore are more likely to come in to closer proximity to one another, thus amplifying the virus," stated Vicki Kramer, Chief of Vector-borne Diseases at the State Department of Public Health.

For more information visit:  
<https://blogs.kqed.org/stateofhealth/2014/09/21/drought-may-be-linked-to-increase-in-west-nile/>  
[www.ochealthinfo.com/phs/about/dcepi/epi/disease/wn](http://www.ochealthinfo.com/phs/about/dcepi/epi/disease/wn)

## Did You Know... ?

In 2015, the world is coming to Los Angeles... will you be there, too?



With 7,000 athletes and 3,000 coaches representing 177 countries, along with 30,000 volunteers and an anticipated 500,000 spectators, the 2015 Special Olympics World Games - being staged in Los Angeles July 25 - August 2, 2015 - will be the largest sports and humanitarian event anywhere in the world in 2015, and the single biggest event in Los Angeles since the 1984 Olympic Games. The 2015 Special Olympics World Games, with the unparalleled spirit, enthusiasm, teamwork, joy and displays of courage and skill that are hallmarks of all Special Olympics events, will feature 25 Olympic-style sports in venues throughout the Los Angeles region.

The Opening Ceremony, to be held July 25, 2015 in the historic Los Angeles Memorial Coliseum, site of the 1932 and 1984 Olympic Games, is expected to attract 80,000 spectators. ESPN will bring coverage of World Games to millions of fans around the world.

DSAOC is an official World Games *Amplifier*, and will continue to help promote the World Games and the efforts around this amazing event. We will be putting together a couple DSAOC groups to participate in the "Fans in the Stands", because "Celebrating begins, not when the athletes cross the finish line or score the winning goal but when the fans erupt with excitement!"

If you are interested and willing to commit to joining our DSAOC "Fans in the Stands" group, please e-mail your interest to Kellie Perez at [kperez@dsaoc.org](mailto:kperez@dsaoc.org). You will need to indicate how many people would be in your party. The tentative dates are Sunday, July 26 and Friday, July 31. Space will be limited and at this point you will need to have your own transportation. We will continue to keep you updated.

*Supportive fans create an atmosphere the athletes crave to excel in competition. Help fill the stands and create that excitement!*

For more information on this exciting event, and how you can become involved, please visit: [www.la2015.org](http://www.la2015.org)

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## DSAOC's Sibshops Program

If your loved one with Down syndrome has siblings, this is something you need to read and consider:

**Brothers and sisters** will be in the lives of family members with Down syndrome longer than anyone. Brothers and sisters will be there after their parents are gone, and special education services are a distant memory.

Throughout their lives, brothers and sisters share many of the apprehensions that parents of children with special needs experience, including guilt, isolation, a need for information, concerns about the future and, eventually, caregiving demands.

Because of the lifelong and important role that siblings can and will play, DSAOC is making a commitment to offer support for siblings of individuals with Down syndrome. DSAOC volunteer, Autumn Trail, a special educator and sibling herself, will facilitate

DSAOC's Sibshops, having recently completed the training with the Sibling Support Project's Director Don Meyer.

**DSAOC's Sibshops** will first be offered for siblings ages 8 through 12, because those are the years when children begin to recognize some of the developmental differences they see in their sibling with Down syndrome. It is a natural time of learning and inquisitiveness.

**What to Expect:** DSAOC's Sibshops will be fun to attend. It will provide peer support and information within a recreational context. It may be "therapeutic" to attend, but it is not therapy. It is a wonderful blend of making friends, having fun, receiving information, and sharing their lives with others. Friendship will be a cornerstone component, as these siblings will likely support one another over the years. The group will plan to meet monthly, most likely on a Saturday or Sunday from 1-4 p.m.

Enroll your child(ren) in DSAOC's Sibshops today by contacting Kristi Golden, DSAOC Program Director, at [programs@dsaoc.org](mailto:programs@dsaoc.org) or call the DSAOC Center at (714) 540-5794. Be sure to list the name and age of the interested sibling and whether Saturday or Sunday is better for you. Thank you!

**Stay Connected**

Visit us on Facebook - [facebook.com/DSAOC](https://www.facebook.com/DSAOC)  
 Visit us on Twitter - [twitter.com/DSAOC](https://twitter.com/DSAOC)  
 Visit our blog - [dsaoc.org/blog](http://dsaoc.org/blog)  
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DOWN SYNDROME ASSOCIATION OF ORANGE COUNTY  
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DSAOC  
 DOWN SYNDROME ASSOCIATION OF ORANGE COUNTY

### FALL 2014

DSAOC strives to create a place for connection, hope and awareness, for people with Down syndrome and their families in Southern California.

**Our Mission** is to provide the means necessary to empower individuals with Down syndrome to reach their full potential.

## 2015 Healthcare Conference



Dennis McGuire Ph.D.  
 Keynote Speaker

# A Healthful Journey

Lifelong Healthcare for Individuals with Down Syndrome

Saturday, February 7, 2015  
 8:30 a.m. to 5:30 p.m. at UC Irvine

Join us in 2015 for a conference that will focus on lifelong healthcare for our loved ones with Down syndrome, including select topics that you shared with us via our survey earlier this year.

**\$85 Per Person Early Bird Registration/ \$100 Per Person Regular Conference Fee**  
**Early Bird Registration will end December 15, 2014, so register early!**

**Register Online Today at:** [www.events.org/cpage.aspx?e=78760](http://www.events.org/cpage.aspx?e=78760)  
**or Call the DSAOC Center (714) 540-5794.**

**Other topics include:**

- Importance of sleep and common sleep disorders
- Nutrition & lifestyle
- The research and diagnosis of Alzheimer's in adults with Down syndrome
- Endocrinology
- Ear, nose and throat
- Gastroenterology
- Dental issues, oral healthcare and orthodontics
- Vision health and signs of vision issues
- A summary: Common healthcare issues for adults with Down syndrome and the screenings that are part of the healthcare guidelines

Down Syndrome Association of Orange County – Regional Center Vendor Number PM1261 (Some Regional Centers in the LA area may pay for a portion of your conference registration fee. You will need to inquire with your child's service coordinator to confirm.)

THE OPTIMIST



## Message from the President

Dear DSAOC Families and Supporters:

As another year comes to a close, we at DSAOC always reflect on all that we have accomplished over these past 12 months. We continue to be grateful for the support we receive from donors and volunteers, because it is with your generosity that we're able to do so much with a year of successful programs, services, activities and events. It is with your support that we can continue to Change Perceptions and Change Lives – **thank you!**

We'd also like to express our gratitude to our three Fall 2014 interns, who collectively volunteered 391 hours with DSAOC, adding their energy and care to all aspects of what we do. Each helped answer your phone calls, find resources, represented DSAOC at resource tables in the community, cheerfully greeted people who came to the center and, of course, helped with our big fall events, the Boo Bash, Trick or Trunk and the Buddy Walk.

We wish them the very best, as they complete their undergraduate degree programs and pursue their careers. Thank you Olivia, Rosie and Shelby!

Our 2015 Conference is coming up on Saturday, February 7, and we hope that all of you can join us. It will be very informative and will include medical professionals from CHOC Children's, UC Irvine and Miller Children's hospitals. We are also thrilled to have Dr. Dennis McGuire as our Keynote Speaker.

Dennis McGuire Ph.D. helped establish the Adult Down Syndrome Center that has served the health and psychosocial needs of over 5,000 adults with Down syndrome since its inception in 1992. His work experience includes over 30 years in the mental health and developmental disabilities fields. He has published numerous articles and co-authored two books and, besides serving as our Keynote Speaker, he will be offering a Q&A at the conclusion of the conference.

**Register today**, either online at [www.events.org/cpage.aspx?e=78760](http://www.events.org/cpage.aspx?e=78760) or by calling the DSAOC Center at (714) 540-5794.

Before I close this message, I wish to ask you to please consider DSAOC during this season of giving. A monetary gift or a gift of your time are both appreciated and needed.

As we move into 2015, we will hit the ground running with some new Teen/Adult programs, our Feeding & Swallowing Therapy Program and our new Sibshops program for siblings of individuals with Down syndrome. We will also continue to offer all of the regular programs, services and resources.

Remember to check our website for videos, resources, updates and our calendar – [www.dsaoc.org](http://www.dsaoc.org). Have a wonderful holiday season and a fantastic start to your 2015!

Sincerely,

Janette Mattson  
President - Board of Directors, DSAOC

**DSA|oe**  
DOWN SYNDROME ASSOCIATION OF ORANGE COUNTY  
CHANGING PERCEPTIONS • CHANGING LIVES

**A PLACE FOR connection hope awareness**

The Down Syndrome Association of Orange County has been serving people with Down syndrome and their families in the greater Orange County community for more than 35 years.

Help us change perceptions and change lives by making an end of year, tax-deductible secure donation at [dsaoc.org](http://dsaoc.org).

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## The Can List

By Kathie Snow

When my son, Benjamin, was very young, he was routinely assessed by professionals, like most children and adults with disabilities, and I was routinely disturbed by these assessments—they told me everything my son could not do. (*Duh!* Tell me something I didn't already know!) As a three-year-old with cerebral palsy, he couldn't sit up, crawl, or walk; didn't have the pincer grasp, protective reflexes, and more; and he had just started talking.

Benjamin was also a happy, funny, and determined kiddo with many abilities. Once he began to talk, he demonstrated an extraordinary auditory memory and the gift of mimicry: he perfectly recited dialogue from "Thomas, the Tank Engine" videos with a British accent!

But because the strengths he did have were not included in the developmental assessments, they didn't count. Thus, based on the tests, he looked like a failure. The child represented by test results was not the child we knew. So we declined formal assessments, opting for informal assessments instead. (See "After Formal Assessments: Do Not Pass Go" at [www.disabilityisnatural.com/explore/children-families](http://www.disabilityisnatural.com/explore/children-families).)

We recognized the importance of focusing on what Benjamin can do, and building on those skills, instead of focusing on—and trying to "fix"—what he cannot do. A formal assessment given today would probably still show him as "deficient," despite his being a successful 23-year-old college student, award-winning filmmaker, and more.

Who is the real person? The one who can't, or the one who can? Who are you? How much time do you spend trying to fix what you can't do? Isn't more time spent building on what you can do? Let's do the right thing: focus on what a child or adult with a disability can do by making a Can-List!

DSAOC website: [www.dsaoc.org](http://www.dsaoc.org)

DSAOC Calendar of events: [www.dsaoc.org/events-calendar.html](http://www.dsaoc.org/events-calendar.html)

CHOC Children's Ds program: [www.dsaoc.org/chocs-children-down-syndrome-program.html](http://www.dsaoc.org/chocs-children-down-syndrome-program.html)

Community Corner: [www.dsaoc.org/community-corner.html](http://www.dsaoc.org/community-corner.html)

National Down Syndrome Society: [www.ndss.org](http://www.ndss.org)

National Down Syndrome Congress: [www.ndscenter.org](http://www.ndscenter.org)

Regional Center of Orange County: [www.rcocdd.com](http://www.rcocdd.com)

International Mosaic Down Syndrome Association: [www.imdsa.org](http://www.imdsa.org)



Important Links

What should be included in the Can-List? A person's abilities, strengths, talents, and/or interests. Stay away from things like the pincer grasp, walking, crawling, reading level, appropriate behavior, etc., that reflect medical-model thinking. (You don't include that stuff when describing your strengths, do you?)

What does the person do well now or want to do? What about unique personality traits, hobbies, interests, and much more! Who should contribute to the list? The person with a disability and the family, plus teachers, friends, professionals, and/or others.

A Can-List creates a more accurate and positive perception of the person, not only in the eyes of others, but also in the eyes of that person. Imagine the possibilities when the Can-List is longer than the Can't-List!

The Can-List can also create new possibilities. What if the Can-List was the first discussion in a team meeting (IEP, ISP, etc.)? In kindergarten, my son had difficulty picking up beans/marbles during counting lessons, but he easily picked up his beloved "Thomas" trains I sent from home.

If a boy collects sports trading cards, his parents and teachers could use those to help him with reading, math (using sports stats, players' numbers, etc.), and more. A middle-school girl who loves fashion, but struggles with reading, can be provided with fashion books, magazines, websites, etc.—she'll be motivated to read about what she loves. An adult who likes to cook (or who wants to learn) can take a cooking class, and that can open the door to friendships, which may lead to a job and more.

When time and effort are spent trying to "fix" a person's "deficits," there's little time left for building on strengths. Time's a-wasting—let's get busy creating a Can-List and enjoy the extraordinary outcomes!



(Kathryn far left, Katelyn second from the left)

## An Opportunity to Serve

In the Spotlight: Katelyn De Sa and Kathryn Erskine



Earlier this year, DSAOC received a call from Katelyn De Sa and her friend Kathryn Erskine. They were interested in participating at some level, so they could earn their high school service hours. After a few conversations and a meeting, Katelyn and Kathryn formalized a plan for their service project, which quickly turned from an opportunity to simply earn their service credits to an opportunity to truly serve. These amazing young ladies put together a plan to create school supply gift bags for the young children in our Mano a Mano early reading program, which is a program for children with Down syndrome growing up in Spanish

language homes that helps them develop a love of learning the English language, and assists the parents in becoming more engaged with their learning.

To raise money for their project, Katelyn and Kathryn coordinated a door-to-door campaign in their community, and sold hundreds of homemade cupcakes at \$2 each. They also organized bake sales at their high school campus and collectively were able to successfully raise \$840! Each child in the Mano a Mano program received an educational gift bag funded by Katelyn and Kathryn's efforts. The additional money raised was donated to the DSAOC program. Our families were overwhelmed with gratitude, and many of the parents expressed how amazed they were to see two 15-year-old girls dedicated to serving their community so passionately.

Thank you Katelyn and Kathryn!

Mark your Calendar for these DSAOC events!

**Saturday, December 13, 2014**  
Breakfast with Santa at CHOC Children's Wade Education Center/ Orange

**Saturday, February 7, 2015**  
DSAOC Healthcare Conference at UC Irvine

**Saturday, February 14, 2015**  
Teen/Adult Red Carpet Ball  
Doubletree Hotel, Santa Ana

**Monday, June 8, 2015**  
DSAOC's 11<sup>th</sup> Annual Golf Tournament,  
Banquet & Auction  
Los Coyotes Country Club, Buena Park

Save the Dates